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A Stepping-stone Towards Sustainable Long-term Care in Europe

Saif Elayan

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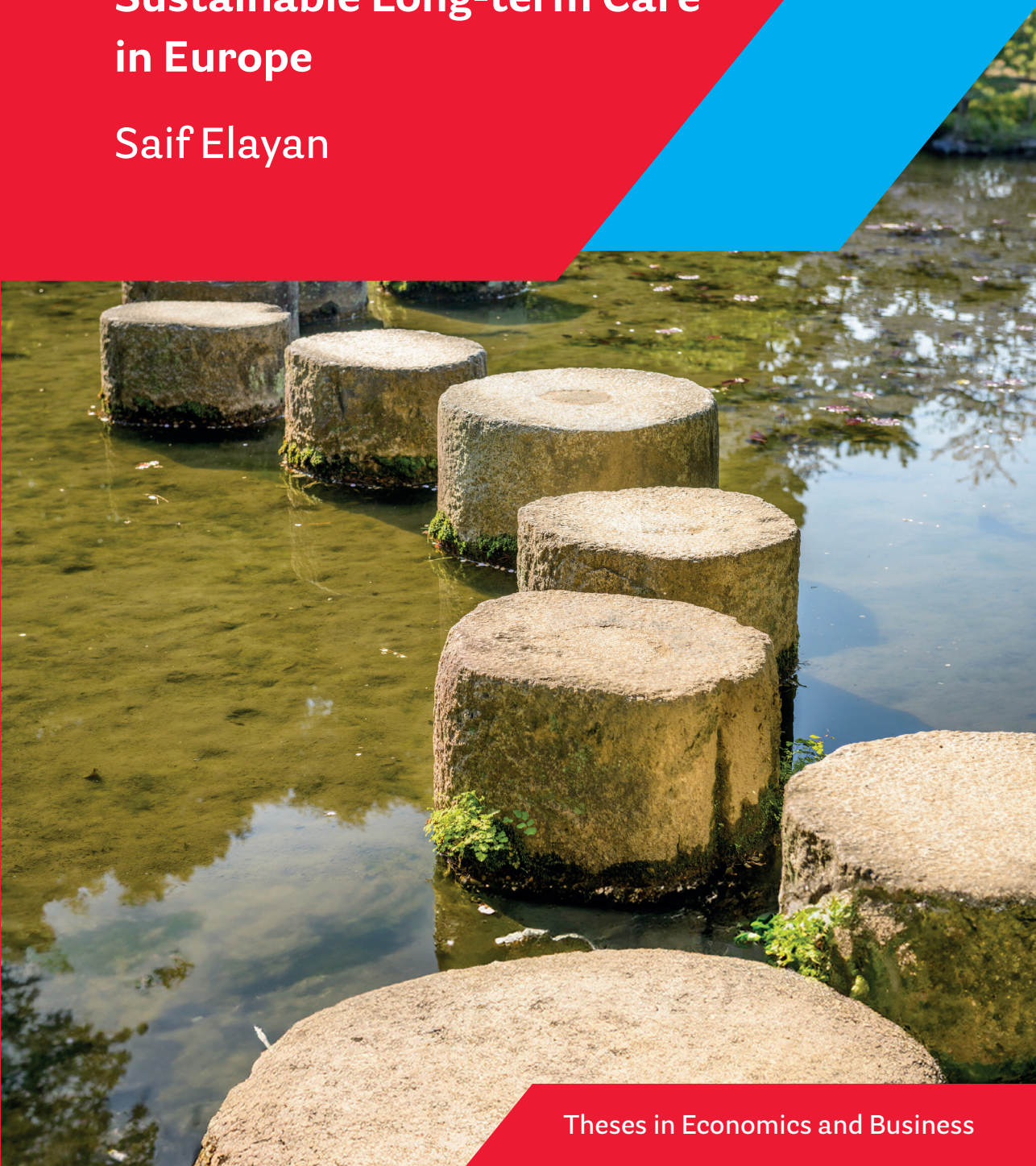

Theses in Economics and Business

A Stepping-stone Towards Sustainable Long-term Care in Europe

Understanding the Impacts of and Demand for Informal Care in Europe

Saif Elayan

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A Stepping-stone Towards Sustainable Long-term Care in Europe

Understanding the Impacts of and Demand for Informal Care in Europe

PhD thesis

to obtain the degree of PhD at the
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on the authority of the
Rector Magnificus Prof. J.M.A. Scherpen
and in accordance with
the decision by the College of Deans.

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by

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Table of Contents

List of Tables

List of Figures

Chapter 1

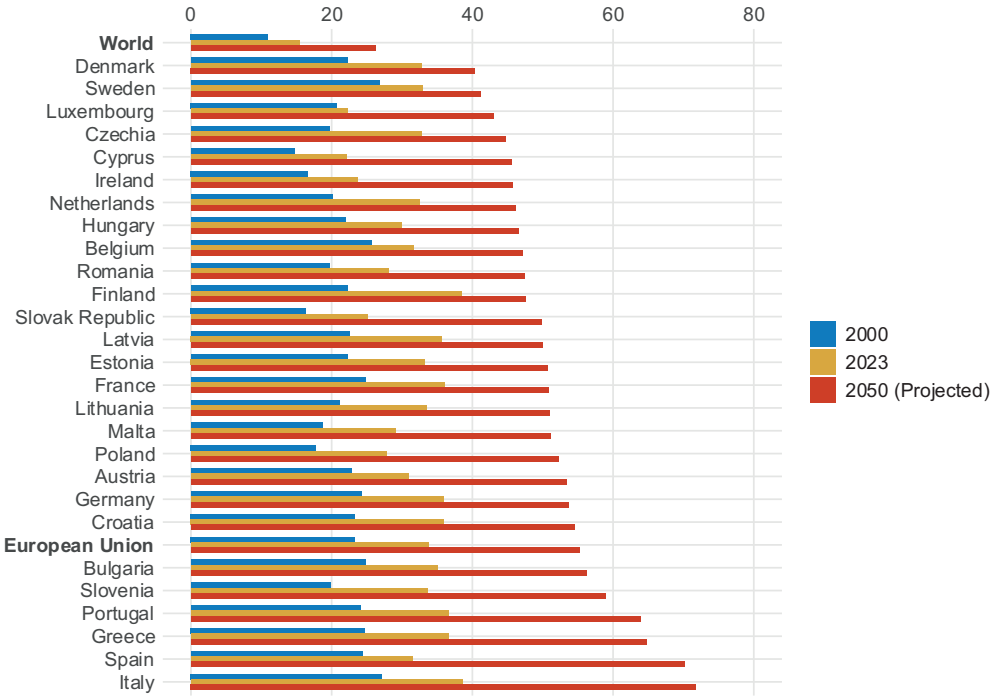
Introduction

1. Introduction

1.1. Background

The demographic landscape of Europe has undergone significant changes since the 1960s. Life expectancy at birth has consistently increased, rising by over two years each decade (European Commission et al., 2020; World Bank, 2022c). Concurrently, life expectancy at age 65 has seen remarkable gains, with Europeans aged 65 in 2022 enjoying a lifespan extended by more than five years compared to their counterparts in 1960 (European Commission et al., 2020; OECD, 2022). Over the same period, fertility rates across European nations markedly declined, dropping to sub-replacement levels. By 2022, these rates had dwindled to some of the lowest globally, resulting in the fewest live births recorded since 1960 (Euronews, 2024). This decline in birth rates, combined with enhanced longevity, has led to a significant demographic shift—the ageing of the European population.

This ageing trend is reflected in the old-age dependency ratio in the European Union (EU), which has more than doubled since 1960, reaching a current figure of 33.8%. This figure substantially exceeds the global average of 15.4%. Currently, nearly one-fifth of the EU's population is aged 65 or older, with projections indicating an increase to 30.9% by 2050 (World Bank, 2022d). Figure 1.1 illustrates the old-age dependency ratios in EU countries for 2000 and 2023, as well as projections for 2050. Across all member states, the ratio is expected to rise significantly, with projections for 2050 ranging from about 40% in Denmark and Sweden to over 70% in Spain and Italy. Furthermore, the average old-age dependency ratio in the EU is projected to surpass 55%, more than doubling the projected global average of 26.2% (World Bank, 2022d).



The old-age dependency ratio represents the number of people aged 65 and over as a proportion of the labour force (aged 15-64).

Source: World Bank

Figure 1.1. *Old-Age Dependency Ratios in the EU for 2000, 2023, and Projections for 2050*

The significant ageing of the population has brought with it inherent health challenges. As the population has aged, the incidence of disabilities, chronic diseases, and frailty has increased, leading to an unparalleled rise in the demand for long-term care (LTC) (Geerts et al., 2012; Kooiker et al., 2019; R. Wittenberg et al., 2008). In response, European nations have implemented a series of policy reforms to reshape the provision of LTC. Central to these reforms is the restricted access to institutional care facilities and an increased reliance on informal caregiving (Verbakel, 2018a). These reforms reflect a broader policy shift aimed at containing costs while meeting the mounting demand for LTC (Jongen et al., 2016). Within this paradigm, informal caregiving has solidified as the linchpin of LTC systems, regarded as a

means to manage growing care needs without straining the financial resources of these systems (Mosca et al., 2016).

Nonetheless, this reliance on informal care is not without detriment, imposing significant externalities on informal caregivers (henceforth, caregivers) that permeate the broader society (Maarse & Jeurissen, 2016). Fast et al. (1999) were among the first to explore these externalities, denoting them as the 'hidden' costs of informal care. These costs include non-economic (intangible) costs associated with health impairments emanating from the physical, mental, and emotional strains that caregivers may endure (Hiel et al., 2015; Kaschowitz & Brandt, 2017). Although increasingly recognised, these costs remain largely disregarded in policy evaluations and resource allocation decisions (Al-Janabi et al., 2016). This omission is often attributed to the lack of data on how caregiving impacts caregivers' health-related quality of life (HRQoL) (Leech et al., 2023). HRQoL is a multidimensional construct widely used in health economics to quantify the health impacts of various activities, health conditions, and interventions (Ustjanauskas & Malcarne, 2020). Assessing caregivers' HRQoL helps capture potential declines in their physical, mental, emotional, and social functioning, allowing their experiences to be integrated into health technology assessments and policy evaluations (Al-Janabi et al., 2016; Bleijlevens et al., 2015; Whitehead & Ali, 2010).

Informal care also entails substantial economic costs. One major component of these costs is the value of the time caregivers dedicate to providing care (Fast et al., 1999). Beyond the value of this unpaid caregiver labour, economic costs include out-of-pocket expenses incurred exclusively because of caregiving duties (Keating et al., 2014). Caregivers also often struggle to balance their caregiving responsibilities with work, sometimes being forced to leave the workforce or experiencing decreases in workplace presence and productivity (Kolodziej et al., 2018; Schmitz & Westphal, 2017; Van Houtven et al., 2013).

These economic costs, however, remain largely 'invisible' within mainstream policymaking discourse. This invisibility inadvertently undermines both the sustainability of informal care and the support available to caregivers while instigating inefficient cost-shifting within the LTC system (B. van den Berg et al., 2004; Weatherly et al., 2014). Moreover, the estimation of these costs remains beset by methodological challenges (Engel et al., 2021). The literature offers a range of estimation methods, each rooted in distinct assumptions and perspectives (Koopmanschap et al., 2008). Nevertheless, this variety often results in substantial discrepancies in cost estimates, highlighting the inherently non-neutral impact of methodological choices (Oliva-Moreno et al., 2019). The absence of consensus regarding the most appropriate estimation approach suggests that employing multiple methods may be necessary to enhance both the reliability of findings and their comparability across studies (Oliva-Moreno et al., 2017).

Another aspect of the sustainability of ongoing reliance on informal care concerns the future demand for such care. Projections by Eurostat anticipate that the demographic aged 50 and above in Europe will expand by 16%, increasing from 183 million in 2019 to 211 million by 2050. Notably, the cohort aged 85 and older is projected to witness the most substantial growth, surging by 115% from 12.5 million to 26.8 million (Eurostat, 2024f). This demographic evolution is set to further amplify the demand for LTC, likely impelling caregivers to take on even greater responsibilities in the future (Ribeiro et al., 2022). Yet, the extent of informal care resources required and available in the future remains obscure, a gap that undermines the ability of policymakers to forge effective care policies to address upcoming shifts in the demand and nature of informal care.

1.2. Research Aims and Thesis Outline

This thesis posits that the sustainability of LTC systems extends beyond their financial viability to involve the assessment of externalities experienced by stakeholders beyond the intended recipients of care. At the centre of these stakeholders are caregivers, who make significant personal sacrifices, dedicating billions of euros' worth of time and resources to providing care. Advancing towards this vision of sustainability requires detailed data on informal care, as well as an examination of the impacts of care provision and their determinants on caregiver health and employment outcomes. Additionally, it necessitates a comprehensive estimation of the societal costs of informal caregiving and reliable projections for the future demand for this vital resource. Focusing on the European context and utilising diverse data sources and methodologies, this thesis aims to examine the externalities of informal care on caregivers' health, time and employment, assess their broader implications, and project the future demand for this essential care.

Building on this foundation, this thesis presents four self-contained articles, each exploring a specific aspect of the caregiving landscape through distinct methodological approaches. The thesis begins by introducing the ENTWINE iCohort Study, a multinational web-based cohort study designed to explore the complex interplay of factors affecting the caregiving experience across Europe. Using data from this study, the thesis then explores the health and labour market effects of informal caregiving. The thesis then turns its lens to state-of-the-art methodologies for estimating the various costs associated with informal care, illustrating their application through a detailed case study of the Netherlands. Finally, the thesis projects the future demand for informal care in selected European countries. The contents of each chapter are outlined as follows:

Chapter 2 presents the ENTWINE iCohort Study, conducted by the ENTWINE consortium between August 2020 and December 2021. The consortium is a Marie Skłodowska-Curie Innovation Training Network (ITN) funded by the European Commission through the Horizon 2020 research programme. This multinational web-based cohort study adopts an intensive longitudinal design, combining a two-wave panel survey (baseline + 6 months follow-up) with optional weekly diary assessments. The cohort comprises 1,872 caregivers and 402 care recipients from nine countries, including those represented in the ENTWINE consortium (Israel, Italy, the Netherlands, Sweden, and the United Kingdom) alongside four additional European countries (Germany, Greece, Ireland, and Poland). These countries represent various European welfare regimes. Greece and Italy constitute the Southern European regime, Germany the Continental (Bismarckian) regime, Ireland and the United Kingdom are part of the Anglo-Saxon regime, and Sweden falls under the Scandinavian regime. The Netherlands shows a unique blend of Scandinavian and Continental patterns, whereas Poland belongs to the Eastern European regime (Eikemo et al., 2008; Widding-Havneraas & Pedersen, 2020).

The motivation behind this study was to investigate how personal, interpersonal, psychological, social, economic, and geographic factors intertwine to influence the experiences and outcomes of informal caregiving for caregivers, care recipients, and society at large. The survey comprised a core module and four additional modules, each addressing specific themes aligned with separate research projects led by various teams within the ENTWINE Consortium.

My involvement in the study spanned the entire research process, including study design, securing ethical clearance, recruiting participants, piloting, data collection, and analysis. A key responsibility was overseeing the programming of the survey environment and managing data collection procedures. These tasks entailed utilising various programming languages and techniques to craft user-friendly survey interfaces, minimise data entry errors, and ensure optimal response and completion rates. Additionally, I was responsible for the data curation

process, which included organising, cleaning, and structuring the collected data to ensure its integrity and usability. This process involved standardising variables across data points and preparing the dataset for subsequent analysis by the research team.

Chapter 3 delves into the health and labour market effects of caregiving among participants from the ENTWINE iCohort Study. This chapter probes into the health impacts of informal care provision, with a particular focus on HRQoL as measured by the EuroQol-5 Dimensions (EQ-5D) instrument. It provides an in-depth examination of HRQoL profiles of caregivers and quantifies reductions in HRQoL by comparing EQ-5D utilities and visual analogue scale (VAS) scores of caregivers to those of the general population. The analysis also scrutinises how individual and contextual factors affect caregiver HRQoL. Additionally, the chapter explores the labour market repercussions of caregiving and the determinants thereof, particularly in relation to reduced working hours and diminished productivity.

The findings revealed a significant association between informal caregiving and adverse health outcomes, as reflected in HRQoL. Compared to general population norms, caregivers' EQ-5D utilities and VAS scores were significantly lower across all examined countries. The mean difference ranged from 0.063 to 0.223 for utilities and from 6.41 to 17.60 for VAS scores. These disparities are on par with or exceed the health impacts of several chronic conditions, such as deafness and psoriasis.

Regarding HRQoL determinants, the intensity of caregiving (as measured by hours of care provided), co-residence with the care recipient, and primary caregiving emerged as key factors associated with lower caregivers' HRQoL. Additionally, having one or more children living in the caregiver's household was linked to poorer HRQoL. Employment showed an association with better caregivers' HRQoL, whereas care recipients' dependence on all activities of daily living (ADL) was related to worse outcomes. Notably, financial support was

not associated with HRQoL benefits. In contrast, respite care correlated with improvements in HRQoL among caregivers providing intense care. In-kind support services, e.g., training, information, and counselling, were negatively associated with the HRQoL of caregivers providing low-intensity care. Lastly, the analysis uncovered significant variations in caregiver HRQoL across countries.

The second part of the chapter focused on the labour market effects of informal care provision. More than one-third of employed caregivers reported reducing their work hours due to caregiving responsibilities, with women disproportionately more likely to do so. The caregiving situation itself was also a significant factor, with co-resident caregivers and those providing intensive care being more likely to cut back on work schedules. Similarly, co-resident caregivers were more likely to experience reduced productivity at work. Findings further indicated that receiving support services was not significantly associated with positive work-related outcomes.

Chapter 4 shifts focus to the methodologies of estimating informal care costs and the utility of such estimates for informing policymaking. Through a detailed case study of the Netherlands, the chapter employs state-of-the-art methods from the field of health economics to estimate both the direct (caregiving time and out-of-pocket expenses) and indirect (productivity) costs of informal caregiving in 2019. These methods include opportunity cost, proxy good, and contingent valuation approaches for valuing informal caregiving time, as well as the human capital and friction cost approaches for estimating indirect (productivity) costs. The cost analysis draws upon multiple data sources, including nationally representative individual-level data collected by the Central Bureau for Social Research, and Statistics Netherlands on informal caregiving in the Netherlands.

The findings revealed that informal caregiving costs accounted for approximately 2.15% to 3.71% of Dutch GDP—nearly equivalent to public spending on LTC (2.67% of GDP). Dutch caregivers provided an estimated 1.55 billion hours of care, equivalent to 842,416 full-time working years. The value of these caregiving hours represented the largest share of informal care costs, with women shouldering approximately 58% of this burden. Indirect (productivity) costs emerged as the second most significant contributor to the total informal care costs, with temporary or prolonged exits from the workforce making up over 90% of these costs. Furthermore, we estimated that between 45.1 million and 210.3 million hours of paid labour were forgone due to informal caregiving, translating into the loss of between 24,568 and 114,537 full-time jobs. These productivity costs were valued at between €1.7 billion and €7.9 billion. Finally, care-related out-of-pocket expenses in the Netherlands were found to be relatively modest, averaging €309 annually.

Chapter 5 integrates longitudinal data from the Survey of Health, Ageing and Retirement in Europe (SHARE) with a time-inhomogeneous Markov multi-state model (MSM) within a microsimulation framework. The chapter projects the future demand for informal care among individuals aged 50 to 100 over the next 50 years, from 2024 to 2074, in six European countries: Germany, Greece, Italy, the Netherlands, Poland, and Sweden. It also delves into the short-term and long-term dynamics of this demand, highlighting changes in both the prevalence and nature of informal care, as well as the evolving profiles of care recipients.

A prominent trend identified is the initial growth in the older population (aged 50–100), followed by a gradual decline as the projection period progresses. Population peaks occur at different times in Germany, Greece, Italy, the Netherlands, and Poland, with all experiencing contraction by the end of the projection window. Sweden, however, presents a notable exception, with a population surge that eventually stabilises in the later stages of the projection period.

In terms of the demand for informal care, Germany, Greece, and Italy exhibit an initial surge, peaking in the 2050s and 2060s, before experiencing a significant decline towards 2074. Poland and Sweden, conversely, are projected to see a continuous upward trend in demand, while the Netherlands is expected to experience a steep increase until the early 2050s, followed by a period of moderate growth. By the end of the projection period in 2074, the increase in the demand for informal care compared to the base year is expected to range from 11% in Greece to 64% in the Netherlands.

The prevalence of dependency is projected to rise across all countries, reaching 39% in Sweden and Greece and 48% in Italy by 2074. The share of individuals receiving informal care is anticipated to follow a similar trend, particularly among the dependent population. The proportion of care provided to this dependent group is anticipated to range from 70% in Sweden to 87% in Poland in 2074. Furthermore, the average age of informal care receivers is projected to increase by 6 to 8 years by the end of the projection period.

1.3. Contributions

This thesis advances the discourse on informal care through empirical data generation, novel applications of methodological advancements, and actionable policy insights to bolster the sustainability of LTC systems across Europe. It introduces a comprehensive multinational cohort, offering a valuable resource for future research. Furthermore, this work delineates the health and economic repercussions of caregiving, identifying critical junctures for policy intervention. By projecting future demands for informal caregiving, the thesis also provides policymakers with the foresight to address emerging challenges proactively. Ultimately, this thesis lays the groundwork for adaptive and sustainable LTC systems that are well-prepared to meet Europe's current and evolving care demands. The detailed contributions unfold progressively across chapters, as follows:

Chapter 2 introduces the ENTWINE iCohort Study, one of the most expansive multinational cohort studies on informal care. This comprehensive dataset captures a broad spectrum of factors that mould the intricate experiences of caregivers and care recipients, offering a distinctive platform for future research endeavours in the realm of informal caregiving. By delineating the unique design, recruitment, and data collection procedures employed, the chapter also serves as a blueprint for future similar research on informal care.

Chapter 3 provides a detailed analysis of HRQoL among caregivers in Europe, quantifying the significant health disparities relative to the general population. This chapter also enhances our understanding of the factors associated with caregivers' health and employment, with a particular focus on vulnerable caregiver groups and the support mechanisms prevalent in European countries. By elucidating the differential associations of these determinants, this chapter delivers essential insights for developing targeted support measures aimed at alleviating the adverse health and employment repercussions of caregiving.

Chapter 4 demonstrates the application of state-of-the-art health economics methodologies to estimate the societal value of informal care. This methodological demonstration sets a precedent by employing, in tandem, a broad range of widely recognised methods, addressing the challenges posed by the lack of consensus in the field. This comprehensive framework provides practical guidance for the economic assessment of informal care costs across various contexts, including for Health Technology Assessment (HTA). Through a detailed case study of the Netherlands, the chapter reveals the societal costs of informal caregiving—a significant yet chronically undervalued resource within national income accounts and conventional economic frameworks. By examining the various types of these costs, the chapter provides policymakers with a nuanced understanding of the broader impacts of LTC policies across the care continuum, along with recommendations for their mitigation.

Chapter 5 offers predictive insights into the evolving landscape of informal caregiving across Europe, detailing the short-term and long-term trends in the demand for informal care. It also highlights anticipated shifts in the prevalence and nature of caregiving, as well as changes in the profiles of care recipients. These forward-looking analyses provide policymakers with vital foresight, facilitating proactive planning and resource allocation to accommodate the anticipated surge in caregiving demand. Methodologically, this chapter employs a novel integration of survival analysis techniques and panel data within a microsimulation framework. This approach maximises the utility of rich longitudinal datasets, allowing for exploring caregiving trajectories across various demographic and socioeconomic groups.

Chapter 2

Cohort Profile: The ENTWINE iCohort Study, a Multinational Longitudinal Web-Based Study of Informal Care

2. Cohort Profile: The ENTWINE iCohort Study, a Multinational Longitudinal Web-Based Study of Informal Care*

Abstract: Informal care is a key pillar of long-term care provision across Europe and will likely play an even greater role in the future. Thus, research that enhances our understanding of caregiving experiences becomes increasingly relevant. The ENTWINE iCohort Study examines the personal, psychological, social, economic, and geographic factors that shape caregiving experiences. Here, we present the baseline cohort of the study and describe its design, recruitment methods, data collection procedures, measures, and early baseline findings. The study was conducted in nine countries: Germany, Greece, Ireland, Israel, Italy, the Netherlands, Poland, Sweden, and the United Kingdom. The study comprised a web-based longitudinal survey (baseline + 6-month follow-up) and optional weekly diary assessments conducted separately with caregivers and care recipients. From 14 August 2020 to 31 August 2021, 1,872 caregivers and 402 care recipients were enrolled at baseline. Participants were recruited via Facebook and, to a lesser extent, via the study website or caregiver/patient organisations. Caregiver participants were predominantly female (87%) and primary caregivers (82%), with a median age of 55 years. A large proportion (80%) held at least post-secondary education, and two-thirds were married/partnered. Over half of the caregivers were employed (53%) and caring for a person with multiple chronic conditions (56%), and nearly three-quarters were caring for either a parent (42%) or a spouse/partner (32%). About three-quarters of care recipient participants were female (77%), not employed (74%), and had at least post-secondary education (77%), with a median age of 55 years. Over half of the care recipients were married/partnered (59%), receiving care primarily from their spouses/partners (61%), and diagnosed with multiple chronic conditions (57%). This study examining numerous potential influences on caregiving experiences provides an opportunity to better understand the multidimensional nature of these experiences. Such data could have implications for developing caregiving services and policies, and for future informal care research.

* This chapter is based on (Elayan, Bei, et al., 2024), published in *PLOS one*.

2.1. Introduction

The population of Europe is shrinking and growing older, albeit to differing degrees and at different rates in different countries (Antczak & Lewandowska-Gwarda, 2019). Increases in life expectancy and reduced fertility rates are the main drivers of this transition (Sciubba, 2020). Life expectancy at birth has been steadily increasing in Europe since the 1960s at a rate of more than two years per decade, reaching an average of 81 years in 2018 (European Commission et al., 2020; World Bank, 2022c). Also, over the same period, the average life expectancy at age 65 years in Europe rose by more than five years, with 65-year-olds in 2018 expected to live around 18.1 to 21.6 more years (European Commission et al., 2020; OECD, 2022; WHO Regional Office for Europe, 2021). As the prevalence of disabilities, chronic diseases and frailty increases with advancing age, an unprecedented increase in the number of people in need of long-term care has been noted in the past few decades (Geerts et al., 2012; Kooiker et al., 2019; R. Wittenberg et al., 2008). This trend is expected to continue in the next 50 years, with average life expectancy at birth reaching 86.1 and 90.3 years for men and women, respectively, by 2070 (European Commission & Directorate-General for Economic and Financial Affairs, 2021). Although European countries have responded to this emerging demand in different ways, the dominant trend is unmistakable: policy reforms that increasingly shift the responsibility for long-term care from the welfare state to informal caregivers (Ranci & Pavolini, 2015; Verbakel, 2018a). As a result, greater expectations and responsibility are now being placed on informal caregivers, who are expected to play an even greater role than their already dominant one in the provision of long-term care. The prevalence of informal care in Europe is already large, with estimates ranging from 9% to 34% among the adult population (Zigante, 2018). However, recent research projects that the number of potential caregivers available per older person will decline uniformly in the upcoming decades, thus increasing pressure on fewer available caregivers (Ribeiro et al., 2022). Considering the growing role of informal caregivers, it is

imperative that we seek ways to ameliorate the potential negative effects of informal care on their health, wellness, and financial well-being so that the informal caregiving 'system' is sustained. Therefore, research that seeks to understand caregiving experiences and outcomes, as well as the underlying factors that shape them, is becoming increasingly relevant and necessary.

As noted in the literature (Broese van Groenou & De Boer, 2016; Hengelaar et al., 2021), informal care is a complex phenomenon, where multiple factors interplay to shape its provision as well as the associated experience and outcomes. These factors include psychological (e.g., personality, attitudes and motivations, relational affection), contextual (e.g., time availability, distance, and the health status of the care recipient) and social (e.g., social network size, perceived support) factors that can either facilitate or hinder care provision, and either exacerbate or ameliorate associated negative experiences and outcomes (Andersen & Newman, 2005; Bauer & Sousa-Poza, 2015; Bengtson & Roberts, 1991; Burr et al., 2005; Carmichael et al., 2010; Cooney & Dykstra, 2011; Jacobs et al., 2018; Pearlin et al., 1990; Pillemer & Suitor, 2006; Smits et al., 2010; Stuifbergen & Van Delden, 2011; Zhou et al., 2021). Informal care decisions and experiences can also be shaped by several macro-level factors, including the availability of support services for informal caregivers, community and private services (e.g., migrant care), as well as assistive technologies (Chiatti et al., 2013; Lindt et al., 2020; Madara Marasinghe, 2016). Furthermore, although informal care is often treated as a 'free' resource in long-term care systems, it is now well established that informal caregivers' time might not be costless, while they also incur substantial economic (Ekman et al., 2021; Oliva-Moreno et al., 2019) and non-economic (e.g., health and well-being) costs (Rodrigues et al., 2013; B. van den Berg et al., 2014). Also, these costs are disproportionate among different groups of informal caregivers (e.g., caregivers of patients with different types

of conditions) and are associated with negative caregiving outcomes (Gardiner et al., 2020; Hulme et al., 2016; Oliveira et al., 2020; Rodrigues et al., 2013; Zhaohui Su et al., 2020).

Given the complex nature of the informal caregiving experience, it is crucial that any attempt to comprehend it takes into account the various intertwined factors that contribute to shaping this experience. With this view in mind, we conducted the ENTWINE iCohort Study on informal care. The ENTWINE iCohort Study is a multi-purpose web-based study with an intensive longitudinal design established in 2020 to examine the range of personal, interpersonal, psychological, social, economic, and geographic factors that may co-shape caregiving experiences and outcomes for diverse groups of informal caregivers and care recipients, and for society, in nine different countries that have different care systems. As such, it offers a unique opportunity for a more nuanced understanding of the caregiving experience and hopefully contributes to the introduction or extension of caregiver-centred support.

The study is conducted by the ENTWINE consortium, a Marie Skłodowska-Curie Innovation Training Network (ITN) funded by the European Commission through the Horizon 2020 research programme. The consortium brings together senior and early-stage researchers to investigate a broad spectrum of challenges in informal caregiving and issues concerning the development and use of innovative psychology-based and technology-based interventions that support the willingness and opportunity to provide informal care.

The objective of this paper is to present the baseline cohort of the ENTWINE iCohort Study and describe the cohort design, recruitment, data collection procedures, measures, early baseline findings, and data access procedure.

2.2. Materials and Methods

2.2.1. Design and Recruitment of Collaborating Countries

The ENTWINE iCohort Study is a multinational web-based cohort study with an intensive longitudinal design that combines a two-wave panel survey (baseline + 6 months follow-up) with optional weekly diary assessments. The entire data collection period spanned from August 2020 to December 2021. The cohort includes caregivers and care recipients from nine countries, including those represented in the ENTWINE consortium (the United Kingdom, the Netherlands, Italy, Sweden, and Israel) and four other European countries (Germany, Greece, Poland, and Ireland). Participating countries were selected to represent different geographic areas (i.e., North, East, West, and South) and typologies of welfare states in Europe (European Commission & Directorate-General for Economic and Financial Affairs, 2016). The initial plan was to administer the surveys in paper and web-based formats; however, the former format was suspended due to COVID-19 pandemic restrictions. The detailed protocol of the study has been published elsewhere (Morrison et al., 2022).

2.2.2. Study Setting and Population

The ENTWINE iCohort Study was conducted in eight European countries and Israel. The total population of participating countries is approximately 300 million, of which around 244 million are aged 18 years or older (Eurostat, 2022; Israel Central Bureau of Statistics, 2020). According to data from the European Quality of Life Survey 2016, the prevalence of informal care in participating European countries amongst adults aged 18 or older ranged from 10% in Ireland to 34% in Greece (Zigante, 2018). In Israel, 30% of adults aged 20 or older are informal caregivers (Rosen et al., 2015). Thus, the estimated total number of adult informal caregivers in all participating countries is approximately 50 million.

The study inclusion criteria, assessed by means of an eligibility survey preceding the baseline survey, were: 1) residing in one of the participating countries; 2) being able to answer the surveys in English, Swedish, German, Dutch, Italian, Greek, Hebrew, or Polish; 3) having access and being able to use the Internet; 4) being aged 18 years or above; and 5) having the self-declared cognitive and physical capacity to complete the surveys. In addition, informal caregivers had to be providing care to an adult (aged ≥ 18 years) with a chronic health condition, disability or any other care need. For care recipients, they had to be receiving care from an adult (aged ≥ 18 years) as a result of a chronic health condition, disability, or any other care need.

2.2.3. Cohort Recruitment

To recruit participants, we employed a coordinated recruitment strategy encompassing digital and non-digital methods. Face-to-face recruitment was also initially planned but cancelled due to COVID-19 lockdowns. Non-digital recruitment methods included radio and newspaper advertisements, conference announcements, distribution of flyers in care settings, and word-of-mouth referrals. Digital recruitment methods included social media postings, and calls for participation published in participating universities' newsletters. Facebook was selected as the primary social media platform for recruitment due to its popularity, advanced targeting and reporting options, as well as the familiarity of the research team with it. Our Facebook recruitment efforts began with free posts on the dedicated Facebook pages we designed for the study (in the eight languages offered), as well as on Facebook pages or groups related to caregivers, older adults, and patients with chronic diseases. To take advantage of Facebook's ability to target specific audiences, we initiated paid targeted advertisements from December 2020 to May 2021. This included image and video advertisements we made visible to Facebook users who met the inclusion criteria regarding age and country of residence. In addition, we further targeted potential participants through the use of keywords and interest groups. Facebook's performance metrics were regularly monitored to gauge and optimise

recruitment performance. Free posts about the study were also published by members of the consortium on Twitter, Instagram and LinkedIn, albeit to a lesser extent than on Facebook.

To further enhance recruitment, we also approached local and international caregiver organisations (e.g., Carers Trust, UK), as well as advocacy groups for older adults and patients with chronic diseases (e.g., The Brain Charity, UK) in order to ask them to distribute emails or newsletters inviting participation in the study to their members. Organisations and groups were not offered any incentives for recruitment efforts. A complete list of all caregiver organisations and advocacy groups involved in the recruitment of participants is shown in Table 2.A.1 in Appendix 2.A. We also used snowball sampling by asking participants if they would agree to provide the email address of their caregiver or care recipient in order to invite them to participate in the study. Inviting the caregiver or care recipient was optional, and individual participation in the study was not contingent upon it.

Irrespective of the recruitment method, all flyers, emails, newsletters and social media postings included information about the study and its eligibility criteria and were available multilingually as appropriate. Recruitment materials also included a (hyper)link to the study website (https://www.entwine-icohort.eu), a contact email address for queries and comments, as well as a (hyper)link or/and a scanning QR code directing to the eligibility survey. Participants were not offered any form of compensation for participating in the study.

2.2.4. Data Collection Procedure

Access to the surveys was provided via Questback Enterprise Feedback Suite® (Questback GmbH, 2020), a specialised survey platform for online data collection. Surveys were accessible via a computer, laptop or any other smart device (e.g., smartphones and tablets). Participants were able to exit any of the survey(s) and return later to complete it from where they left off—even on another device. Cookies were not used in order to maintain

confidentiality and to allow multiple respondents to complete the surveys using the same device (e.g., a device shared by a caregiver and their care recipient). In accordance with the General Data Protection Regulation (GDPR) 2016/679, respondents' IP addresses were not recorded or made available to the research team.

As a first step, potential participants who were directed to the link to the eligibility survey were required to answer a series of screening questions to confirm their eligibility before enrolment. Those confirmed as eligible were then required to read a participant information sheet and a consent form and to provide their e-mail address. Upon providing their consent and email address, each participant was sent an invitation email. This email included copies of the participant information sheet and the signed digital consent form, as well as a personalised link to the baseline web-based survey. The survey link was valid for three weeks and, if necessary, a maximum of two reminder emails were automatically sent within a week of the invitation. All participants invited to participate in the baseline survey after 31 May 2021 were informed that they would not take part in the follow-up study as they could not meet the deadline for data collection (15 December 2021).

On accessing the baseline survey link, participants were automatically assigned unique pseudonyms (i.e., artificial identifiers) by Questback to obscure their email addresses. This pseudonymisation technique was used to prevent duplicate participation and protect participants' rights to privacy while still allowing for longitudinal data collection and matching responses across study surveys. After being invited to complete the baseline survey, participants, regardless of whether they completed all parts of the baseline survey, were invited to participate in a weekly diary study. The weekly diary assessments were delivered online once per week for 24 consecutive weeks. Participants in the diary study received various reminder and motivational emails. At the end of the diary study period, regardless of whether they had completed all weeks or not, participants were invited to the follow-up survey. The invitations

were sent via email and contained a personalised link to the follow-up survey that was valid for two weeks. As in the baseline survey, reminder emails were sent to those who had not completed the follow-up survey, three and seven days after receiving the invitation.

2.2.5. Surveys

2.2.5.1. Survey Environment

All study surveys were built using Questback Enterprise Feedback Suite® (Questback GmbH, 2020). In addition to pre-made Questback library questions and themes, free programming languages including HyperText Markup Language (HTML), Cascading Style Sheets (CSS), the Hypertext Preprocessor (PHP), and JavaScript were used to create working personalised dynamic surveys. Dynamic features included question routing (i.e., hiding questions based on answers or combinations of answers to previous questions), text substitution (i.e., feeding answers into subsequent questions), database links (e.g., presenting the surveys in participant's indicated preferred language), randomisation of survey modules (see below), and response validation (e.g., pointing out missing questions, incorrect response format, and potential data entry mistakes through plausibility checks). These dynamic features contributed to the user-friendliness of the survey, low data entry errors, as well as favourable response and completion rates.

2.2.5.2. Surveys' Contents

The eligibility survey started with a question about the language (amongst all offered languages) in which potential participants would prefer to complete the survey. Respondents were also asked how they had heard about the study in order to inform ongoing recruitment efforts. Respondents were next presented with a brief eligibility screener based on the predefined inclusion and exclusion criteria described earlier: this included three questions on age, country of residence, and their caregiving or care-receiving status. The latter question was

a single-answer multiple-choice question with the following answer options: 'I provide care for a family member or a friend with a chronic health condition, disability or any other care need that is 18 years old or over'; 'I receive care from a family member or a friend, that is 18 years old or older, due to my chronic health condition, disability or any other care need'; and 'None of the above'. Based on their answer to this question, eligible participants were assigned to either the caregiver or care recipient sample. Conversely, respondents who selected 'None of the above' were deemed ineligible, as they did not meet the criteria of being caregivers or care recipients, and thus, were screened out and not included in the study. We purposefully used a wide definition of informal care without restrictions on the health condition(s) and the level of impairment of the care recipient; the social relationship between the caregiver and care recipient; or the intensity of caregiving. The last two questions concerned whether participants would like to be contacted about future research and whether they would like to receive a summary of key findings upon study completion.

Caregiver and Care Recipient baseline surveys comprised five module sections: a core module and four additional modules, each addressing a specific theme related to informal caregiving. The core module assessed sociodemographics and aspects of the care situation and included validated questionnaires targeting key dimensions of the caregiving experience (e.g., well-being, willingness to provide care, and relationship characteristics). The additional four modules were dedicated to specific themes: Module 1, cultural and psychosocial aspects; Module 2, personality and geographical barriers; Module 3, interpersonal processes; and Module 4, employment, costs and use of formal care services (including migrant care).

In the Caregiver Baseline Survey, all caregivers were asked to complete the core module (approximately 20 to 30 minutes to complete) and three randomly assigned and ordered modules (each approximately 10 minutes to complete). The decision to randomly assign three out of the four additional modules was made to shorten the survey and reduce its response

burden, thereby improving the response rate. The Care Recipient Baseline Survey was shorter (approximately 40 minutes to complete); therefore, care recipients were asked to complete the core module and all four additional modules (randomly ordered).

Caregiver and Care Recipient Follow-up surveys included the same questions as the baseline surveys (minus demographics) as well as additional questions about whether participants still provide/receive care. A summary of the measures used in the ENTWINE iCohort baseline surveys is provided in Table 2.1. Details about the measures used for this study are reported in a previous paper (Morrison et al., 2022).

Table 2.1. *A Summary of the Measures Used in the ENTWINE iCohort Baseline Surveys*

Module/Topic	Measure(s)	Max number of items	Answer type	CG[a] Baseline Survey	CR[b] Baseline Survey
Core Module					
Caregiver sociodemographic characteristics	Items concerning age; gender; home location; the highest level of attained education; partnership status; the number of dependants, siblings and living parents; employment status; income; religion; ethnicity; migration background; the number of care recipients; own health condition(s); relationship to the care recipient; caregiving duration and frequency; the presence of other caregiver(s); previous care experience; and distance to the care recipient	47	Yes/no, multiple-choice, and numerical/ text fields	✓	✗
Care recipient sociodemographic characteristics (as reported by the caregiver)	Items concerning age, gender, health condition(s) of the care recipient, length of illness, and living arrangements	32	Yes/no, multiple-choice, and numerical/ text fields	✓	✗
Care recipient sociodemographic characteristics	Items concerning age; gender; home location; the highest level of attained education; partnership status; the number of dependants, siblings and living parents; employment status; income; religion; ethnicity; migration background; own health condition(s); relationship to the caregiver; caregiving duration and frequency; the presence of other caregiver(s); living arrangements; and distance to the caregiver	58	Yes/no, multiple-choice, and numerical/ text fields	✗	✓
The importance of religion	Single item: What is the importance of religion in your life?	1	Likert scale	✓	✓
Perceived interpersonal connectedness	Inclusion of Other in the Self Scale (IOS) (Aron et al., 1992)	1	Likert scale	✓	✓
The capacity of the care recipient to perform activities of daily living	Katz Index of Independence in Activities of Daily Living (ADL) (Katz, 1983)	6	Yes/no	✓	✓

Module/Topic	Measure(s)	Max number of items	Answer type	CG[a] Baseline Survey	CR[b] Baseline Survey
Time devoted to helping with household activities, personal care, and practical and emotional support	Caregiver Indirect and Informal Care Cost Assessment Questionnaire (Landfeldt et al., 2019)	4	Numerical fields	✓	✗
COVID-19 related	Items related to COVID-19 diagnosis and to assess the impact of COVID-19 on the caregiver's employment, access to support services, willingness to care, provision of practical, emotional and personal care	15	Multiple-choice and numerical fields	✓	✗
The use of paid home care	Items asking about the use of paid home care and the demographics of paid care workers	35	Yes/no and multiple-choice	✓	✓
Caregiver financial benefits	Items asking about the receipt of cash benefits, financial compensation during care leave, tax benefits, coverage of social or pension contributions, caregiver credits, and health insurance	6	Yes/no and numerical fields	✓	✗
Caregiver support services	Items asking about the receipt of caregiver support services	22	Yes/no, multiple-choice, and numerical/ text fields	✓	✗
Motivations to provide care	Motivations in Elder Care Scale (MECS) (Lyonette & Yardley, 2003)	13	Likert scale	✓	✗
Communal motivation to care	Partner-Specific Communal Motivation Scale (CMS) (Lemay Jr. & Neal, 2013)	10	Likert scale	✓	✓ (adapted)
Willingness and ability to provide care	Willingness to Care Scale (Abell, 2001)	30	Yes/no and Likert scale	✓	✗
Willingness to receive care	Items to assess the willingness to receive care. Adapted from Abell (Abell, 2001)	3	Likert scale	✗	✓
Well-being	The World Health Organisation-Five Well-Being Index (WHO-5) (Hermanns, 2007)	5	Likert scale	✓	✓
Perceived gains associated with caregiving	The GAINS Scale (Pearlin, 1988)	10	Likert scale	✓	✗
Caregiver burden	Short-Form Zarit Burden Interview (ZBI-12) (Bédard et al., 2001)	12	Likert scale	✓	✗
Health-related quality of life	EuroQol-5D (EQ-5D-5L) (Herdman et al., 2011)	6	Likert scale	✓	✓
Depression	Centre for Epidemiological Studies Depression Scale (CESD-10) (Miller et al., 2008; Radloff, 1977)	10	Likert scale	✓	✓
Positive dyadic interactions and negative dyadic strain	Dyadic Relationship Scale (DRS) (Sebern & Whitlatch, 2007)	11	Likert scale	✓	✓ (10 items)
Relationship satisfaction	Relationship satisfaction (RAS) (Hendrick et al., 1998)	1	Likert scale	✓	✓
Module 1: Cultural and psychosocial aspects					
Familism	Revised Familism Scale (RFS) (Losada et al., 2020)	21	Likert scale	✓	✓
Cognitive and emotional representations of illness.	Brief Illness Perception Questionnaire (B-IPQ) (Broadbent et al., 2006)	9	Likert scale	✓	✓
Meaning in life	Meaning in Life Questionnaire (MLQ) (Steger et al., 2006)	5	Likert scale	✓	✓

Module/Topic	Measure(s)	Max number of items	Answer type	CG[a] Baseline Survey	CR[b] Baseline Survey
Personal values	Portrait Values Questionnaire (PVQ-21) (Schwartz, 2003)	9	Likert scale	✓	✓
Perceived choice in assuming the caregiving role	Single item: Do you feel you had a choice in taking on this responsibility of caring for your loved one?	1	Yes/no	✓	✗
Module 2: Personality and geographical barriers					
Geographic-related questions	Items concerning care setting and access, and perceived geographical barriers and facilitators to informal care provision	30	Yes/no, multiple-choice, and numerical/ text fields	✓	✓ (8 items)
Personality	Big-Five Inventory Extra Short Form (BFI-2-XS) (Soto & John, 2017)	15	Likert scale	✓	✓
Attachment patterns	The Relationship Structures Questionnaire of the Experiences in Close Relationships—Revised (ECR-RS) (Fraley et al., 2011)	9	Likert scale	✓	✓
Empathy	Toronto Empathy Questionnaire (TEQ) (Spreng et al., 2009)	16	Likert scale	✓	✓
Individuals' personal mastery	The Pearlin Mastery Scale (Pearlin & Schooler, 1978)	7	Likert scale	✓	✓
Module 3: Interpersonal processes					
Collaboration between caregiver and care recipient	Perception of Collaboration Questionnaire (PCQ) (C. A. Berg et al., 2008)	9	Likert scale	✓	✓
Perceived communication and dyadic coping within a close relationship when one or both dyad members are stressed	Dyadic Coping Inventory (DCI)-communication subscale (Bodenmann, 2000)	8	Likert scale	✓	✓
Mutuality across four dimensions: love and affection, shared pleasurable activities, shared values, and reciprocity	Mutuality Scale (MS) (Archbold et al., 1990)	15	Likert scale	✓	✓
Perceived partner responsiveness	The perceived partner responsiveness scale (PPRS) (Reis et al., 2017)	12	Likert scale	✓	✓
Perceived (un)supportive behaviours	Social Support List (SSL) (Kempen & Van Eijk, 1995)	13	Likert scale	✓	✓
Module 4: Employment, costs, and migrant care work					
The impact of informal care on employment	Caregiver Indirect and Informal Care Cost Assessment Questionnaire (Landfeldt et al., 2019)	7	Yes/no, numerical fields, and Likert scale	✓	✗
Types of home care services provided by paid care workers	Items asking which tasks and how many hours of care tasks (total and per type of care task) are provided by paid home care workers	18	Yes/no, and numerical fields	✓	✗
The rationale for the hiring of paid care workers	Items assess the rationale for hiring paid home care workers and the decision to hire or not hire migrant care workers	22	Yes/no	✓	✓

Module/Topic	Measure(s)	Max number of items	Answer type	CG[a] Baseline Survey	CR[b] Baseline Survey
Out-of-pocket expenses incurred due to caregiving provision	Items to measure out-of-pocket costs (both in terms of the overall total and per type of cost) incurred by caregivers	25	Yes/no, and numerical fields	✓	✗
Care benefits received by the care recipient	Items to measure care benefits received (both in terms of the overall total and per type of care benefit)	4	Yes/no, and numerical fields	✗	✓
The use of, and the out-of-pocket expenses for, care services, as well as assistive devices and aids used by the care recipient	Items concerning the types of services the care recipient receives in relation to their care and the out-of-pocket expenses spent in relation to their care	22	Yes/no, and numerical fields	✗	✓

[a]CG = Caregiver
[b]CR = Care recipient

In this article, we focus on characterising the cohort at baseline in terms of key sociodemographics (i.e., age, gender, marital status, education and employment status), caregiving situation characteristics (i.e., care intensity, primary caregiving, and kinship type), and care recipient's health condition(s) and dependency. Furthermore, we consider the willingness and ability to provide care, gains and burden from caregiving, and well-being.

The dependency level of care recipients was assessed using the Katz Index of Independence in Activities of Daily Living (ADL). This instrument measures independence in performing six basic ADL: bathing, dressing, toileting, transferring, continence, and feeding. Each of these ADL is scored as 1 for independence and 0 for dependence, and the Katz index score is obtained by totalling these individual scores (Katz, 1983). The score indicates complete independence (score = 6), partial dependence (score 3–5), or severe dependence (score ≤ 2) (Wallace & Shelkey, 2008).

Caregiver willingness and ability to provide care were measured using the Willingness to Care Scale. The scale comprises 30 items, each representing a specific emotional, instrumental, or nursing care task. The ability to perform each task was scored as either 'able' or 'not able', and the willingness to carry out the task was rated on a 5-point Likert scale, ranging from 'completely unwilling' (1) to 'completely willing' (5). The ability-to-care score

was computed by summing up the 'able' responses, while the willingness-to-care score was calculated by averaging the ratings on the 5-point Likert scale (Abell, 2001).

Caregiver gains were assessed using the GAINS scale. The scale comprises ten items, each scored on a 4-point Likert scale ranging from 0 ('not at all') to 3 ('a lot'). The total score was calculated by adding the points for each item (Pearlin, 1988). Caregiver burden was measured using the Short-Form Zarit Burden Interview (ZBI-12). This instrument includes 12 items, each rated on a 6-point Likert scale from 0 ('never') to 5 ('nearly always'). The total score was obtained by summing the ratings of each item, resulting in a possible range from 0 to 60, with higher scores indicating higher levels of burden (Bédard et al., 2001).

The well-being of caregivers and care recipients was evaluated using the World Health Organisation-Five Well-Being Index (WHO-5). The instrument consists of five positively worded statements related to well-being, each scored on a scale of 0 ('at no time') to 5 ('all of the time'). The sum of the scores for the five items (raw score) is multiplied by four, resulting in a percentage score ranging from 0 (worst imaginable well-being) to 100 (highest imaginable well-being) (Hermanns, 2007).

2.2.5.3. Translation and Piloting of the Surveys

All study surveys were first developed in English and then translated into the local languages of the participating countries (Polish, Italian, Dutch, Swedish, Greek, Hebrew and German) using the forward-backward translation approach (World Health Organization, 2016). Validated translations of questionnaires and scales were used wherever available, and those not available in the local languages of participating countries were translated after permission from the authors. The forward translation was conducted by professional bilingual translators who were native speakers of the target languages and fluent in English. The forward translation was translated back into English by independent professional bilingual translators who did not

participate in the forward translation process. The forward and backward translations were then reviewed by members of the research team who are native in the target languages, and all identified inconsistencies were resolved in consultation with the translators involved. Before agreement on the final versions, web-based versions of the translated surveys were created and then tested and piloted in two phases.

The surveys were tested in-house by the research team and ENTWINE consortium members whose mother tongue is the target language. The purpose of the testing phase was twofold. First, all testers (n = 17) were asked to check the technical functionality of the surveys. This included accessibility, readability, formatting, questions' routing, response validation features, and data collection procedures (e.g., invitations and reminders). Second, testers were asked to provide feedback on the translation, time to complete the survey, questions' comprehension and flow, and language consistency. This phase did not uncover any major technical problems, and the surveys functioned as intended on all devices and browsers tested. Testers' comments on the content of the surveys were minor, and changes and refinements were made accordingly. Second, the surveys were pilot-tested using a convenience sample of 25 caregivers and 21 care recipients. Pilot participants were given the opportunity to provide typed feedback on the clarity and understandability of the questions and on any particular problems encountered in completing the surveys. Pilot data were analysed to check for any abnormal patterns of response (e.g., straight-lining) and non-response and to assess the surveys' length and the quality of free-text responses. Based on pilot feedback and data, the research team further refined the surveys for clarity, and time and ease of completion. These refinements included rewording some items and instructions, shortening the survey by eliminating some questions and using shorter questionnaires, and reducing the number of questions per page to avoid excessive scrolling.

2.2.6. Ethics and Governance

Ethical approvals for the study and its consent procedure were obtained from multiple institutions across the participating countries: Institutional Review Board, Bangor University, The UK; NHS Research Ethics and Governance Committee, The UK (reference number: 20/WA/0006); Central Ethics Review Board non-WMO studies, University Medical Center Groningen, The Netherlands (reference number: 201900810); Bar-Ilan University, Faculty of Social Sciences, Department of Psychology, Ethics Committee, Israel (reference number: 36-20); Commissione Etica per la Ricerca in Psicologia (CERPS), Università Cattolica del Sacro Cuore di Milano, Italy (reference number: 31-20); Swedish Ethical Review Authority, Uppsala University, Sweden (reference number: 2020-04569); and Medical Ethics Committee, University of Oldenburg, Germany (reference number: 2020-155). In Poland, the ethical board of the Institute of Psychology at the University of Wrocław recognised the UK NHS Research Ethics Approval as sufficient for conducting the study. Similarly, in Greece, the Department of Psychology at the University of Crete acknowledged the ethical approval granted by the University Medical Center Groningen on the basis of approvals from other European nations. In Ireland, Care Alliance Ireland, a registered charity, deemed the ethical approval from Bangor University sufficient for participant recruitment and study conduct. All these ethical approvals were obtained before initiating recruitment, enrolment, and data collection. All participants were required to give informed written consent via the survey platform Questback before they could gain access to the surveys. Individuals who did not provide consent were denied participation and redirected to a page thanking them for their interest.

2.3. Findings to Date

2.3.1. Recruitment and Inclusion

Baseline recruitment was staggered over the 12-month baseline data collection period from 14 August 2020 to 31 August 2021. The start dates for recruitment varied by country as follows: the UK, Ireland, and Poland on 14 August 2020; Italy on 25 August 2020; the Netherlands on 14 October 2020; Sweden on 23 October 2020; Greece on 31 October 2020; and Germany and Israel on 16 February 2021. Baseline recruitment was concluded on 31 May 2021 in all countries except Germany and Israel. In these two countries, recruitment was extended until 31 August 2021, thereby ensuring a recruitment period of at least six months in all participating countries.

Figure 2.1 illustrates the dates for key recruitment activities and the number of participants enrolled in the cohort in each month of baseline recruitment. Overall, recruitment proceeded slowly until 1 December 2020, with a mean of 124 recruited participants per month. Then the Facebook paid campaign was launched for five months (until 1 May 2021), during which the monthly enrolment rate averaged 318 recruited participants per month. The monthly enrolment rate for the rest of the recruitment period (1 May 2021 through 31 August 2021) was 48 participants per month. The intended duration for baseline recruitment was six months, but it was decided to extend it for six months to recruit a minimum of 2000 participants.

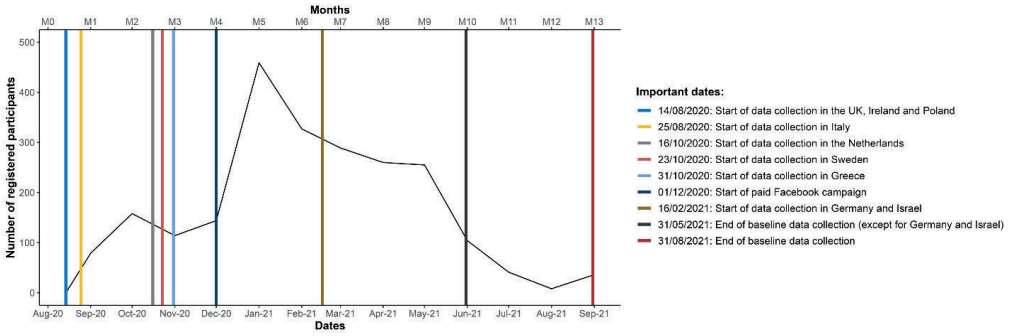


Figure 2.1. *Number of Participants Enrolled in the Cohort in Each Month of the Baseline Recruitment Period*

By the end of baseline recruitment, the link to the eligibility survey had 149,129 hits. The number of visitors who completed at least the first question of the eligibility survey was 24,945 (16.7%), of which 18,685 (75.0%) were excluded due to not completing the survey further, consent withdrawal, or missing the deadline of data collection in their respective country of residence. Out of the 6,260 respondents who completed the eligibility survey, 2,893 (46.2%) did not meet the study's eligibility criteria. This left 3,367 participants available for the study, comprising 2,731 caregivers (81.1%) and 636 care recipients (18.9%). At baseline, 859 caregivers (31.5%) and 234 care recipients (36.8%) either did not access the baseline survey on receipt of the link sent or could not be contacted (i.e., provided incorrect email address). Thus, a total of 1,872 caregivers and 402 care recipients were enrolled in the cohort. The flow chart of recruitment is shown in Figure 2.2.

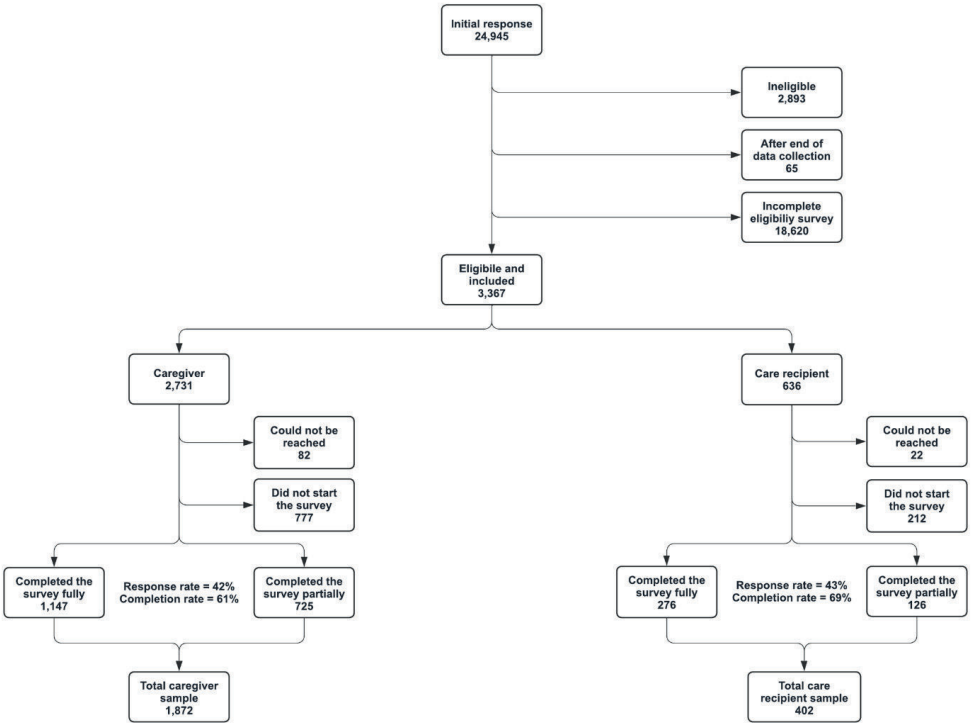


Figure 2.2. *Flow Chart of Baseline Recruitment for the ENTWINE iCohort Study*

The number of unique visitors to the eligibility survey could not be determined, as IP addresses were not recorded and cookies were not used, as stated above. Therefore, response and completion rates could not be computed for the eligibility survey. For the Caregiver and Care Recipient baseline surveys, the response rate, defined here as the number of fully completed surveys by the number of invitation emails sent, was 42% and 43%, respectively (The American Association for Public Opinion Research, 2016). The completion rate (i.e., the number of fully completed surveys by the number of participants who accessed the survey) for the Caregiver and Care Recipient baseline surveys was 61% and 69%, respectively (The American Association for Public Opinion Research, 2016).

The majority of the ENTWINE iCohort were recruited through social media (n = 1,664, 73.2%), especially Facebook. Each of the other recruitment methods yielded less than 8% of the total cohort sample. Figure 2.3 displays the number and percentage of participants enrolled by each recruitment method.

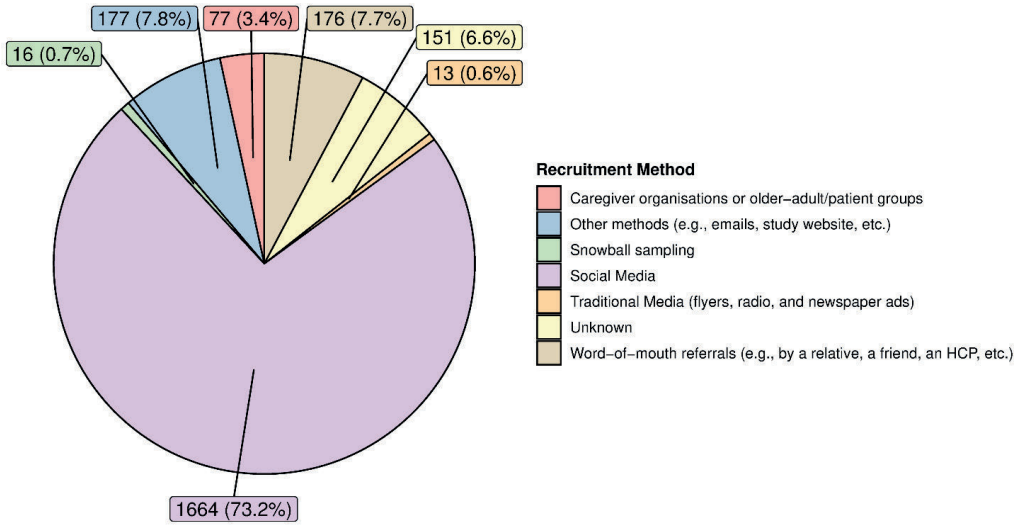


Figure 2.3. *Number and Percentage of Participants Enrolled by Each Recruitment Method*

2.3.2. Baseline Cohort Characteristics

2.3.2.1. Characteristics of Caregiver Participants

The baseline characteristics of caregiver participants and their care recipients overall and by country are presented in Table 2.2. The majority of caregiver participants in all countries were females (87.2%). The median age of the caregiver sample was 55 years, with the youngest age in Poland (50y), Greece, Israel, and Italy (53y) and the oldest in Ireland (56y), the Netherlands (57y), the UK (58y), and Sweden (61y). Nearly two-thirds of caregiver participants (66.7%) indicated being married or in a partnership, with some variation across countries

(54.4% in Greece to 73.7% in Sweden). Across all countries, more than half of the participants (52.6%) were employed, with the percentages somewhat lower in Ireland (34.1%), the UK (40.3%), and Sweden (43.6%). More than 80% of participants held at least post-secondary education (i.e., tertiary vocational or academic education). The majority of caregiver participants reported being the primary caregiver for the care recipient they cared for (82.2%) and providing, on average, 50.5 hours of care per week.

Table 2.2. *Baseline Characteristics of Caregiver Participants and Their Care Recipients Overall and by Country*

Characteristic	N	Germany, N = 38	Greece, N = 160	Ireland, N = 91	Israel, N = 215	Italy, N = 391	Netherlands, N = 421	Poland, N = 171	Sweden, N = 156	UK, N = 229	Overall, N = 1,872
Age, Median (SD)	1872	59.0 (13.5)	53.0 (11.5)	56.0 (11.2)	53.0 (15.6)	53.0 (11.7)	57.0 (11.1)	50.0 (12.9)	61.0 (13.2)	58.0 (12.4)	55.0 (12.8)
Gender, n (%)	1872										
Female		28 (73.7%)	138 (86.2%)	81 (89.0%)	169 (78.6%)	336 (85.9%)	385 (91.4%)	154 (90.1%)	137 (87.8%)	205 (89.5%)	1,633 (87.2%)
Male		9 (23.7%)	21 (13.1%)	7 (7.7%)	45 (20.9%)	50 (12.8%)	33 (7.8%)	17 (9.9%)	19 (12.2%)	23 (10.0%)	224 (12.0%)
Non-binary /third gender		0 (0.0%)	1 (0.6%)	0 (0.0%)	0 (0.0%)	1 (0.3%)	1 (0.2%)	0 (0.0%)	0 (0.0%)	1 (0.4%)	4 (0.2%)
Prefer to self-describe		0 (0.0%)	0 (0.0%)	2 (2.2%)	1 (0.5%)	1 (0.3%)	2 (0.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	6 (0.3%)
Prefer not to say		1 (2.6%)	0 (0.0%)	1 (1.1%)	0 (0.0%)	3 (0.8%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	5 (0.3%)
Marital status, n (%)	1872										
Single		6 (15.8%)	36 (22.5%)	14 (15.4%)	47 (21.9%)	104 (26.6%)	38 (9.0%)	39 (22.8%)	12 (7.7%)	22 (9.6%)	318 (17.0%)
Married or in a partnership		26 (68.4%)	87 (54.4%)	65 (71.4%)	141 (65.6%)	243 (62.1%)	301 (71.5%)	102 (59.6%)	115 (73.7%)	168 (73.4%)	1,248 (66.7%)
Divorced		6 (15.8%)	23 (14.4%)	7 (7.7%)	21 (9.8%)	25 (6.4%)	37 (8.8%)	18 (10.5%)	18 (11.5%)	26 (11.4%)	181 (9.7%)
Widowed		0 (0.0%)	10 (6.2%)	1 (1.1%)	4 (1.9%)	7 (1.8%)	11 (2.6%)	8 (4.7%)	6 (3.8%)	9 (3.9%)	56 (3.0%)
Other		0 (0.0%)	4 (2.5%)	4 (4.4%)	2 (0.9%)	12 (3.1%)	34 (8.1%)	4 (2.3%)	5 (3.2%)	4 (1.7%)	69 (3.7%)
Employed = Yes, n (%)	1837	20 (54.1%)	90 (57.3%)	30 (34.1%)	145 (68.1%)	199 (51.7%)	224 (54.5%)	99 (60.4%)	68 (43.6%)	91 (40.3%)	966 (52.6%)
Missing		1	3	3	2	6	10	7	0	3	35
Education, n (%)	1872										
Primary		0 (0.0%)	5 (3.1%)	4 (4.4%)	1 (0.5%)	2 (0.5%)	5 (1.2%)	0 (0.0%)	8 (5.1%)	1 (0.4%)	26 (1.4%)
Secondary		2 (5.3%)	37 (23.1%)	13 (14.3%)	36 (16.7%)	29 (7.4%)	68 (16.2%)	17 (9.9%)	24 (15.4%)	38 (16.6%)	264 (14.1%)
Post-secondary vocational education		19 (50.0%)	41 (25.6%)	20 (22.0%)	31 (14.4%)	185 (47.3%)	298 (70.8%)	34 (19.9%)	34 (21.8%)	64 (27.9%)	726 (38.8%)

Characteristic	N	Germany, N = 38	Greece, N = 160	Ireland, N = 91	Israel, N = 215	Italy, N = 391	Netherlands, N = 421	Poland, N = 171	Sweden, N = 156	UK, N = 229	Overall, N = 1,872
Post-secondary academic education		14 (36.8%)	75 (46.9%)	53 (58.2%)	145 (67.4%)	173 (44.2%)	42 (10.0%)	105 (61.4%)	86 (55.1%)	124 (54.1%)	817 (43.6%)
Not listed or other		3 (7.9%)	2 (1.2%)	1 (1.1%)	2 (0.9%)	2 (0.5%)	8 (1.9%)	15 (8.8%)	4 (2.6%)	2 (0.9%)	39 (2.1%)
Primary caregiver = Yes, n (%)	1581	29 (78.4%)	103 (74.1%)	69 (93.2%)	119 (64.0%)	257 (79.1%)	307 (88.5%)	107 (82.3%)	130 (90.9%)	179 (89.5%)	1,300 (82.2%)
Missing		1	21	17	29	66	74	41	13	29	291
Total weekly hours of care, Mean (SD)	1604	59.8 (41.3)	47.2 (35.1)	71.7 (40.8)	28.9 (31.5)	64.6 (41.2)	38.3 (35.2)	61.6 (39.8)	40.6 (32.8)	61.4 (39.9)	50.5 (39.7)
Missing		1	19	16	26	62	68	39	12	25	268
WHO-5 score[a], Mean (SD)	1368	48.9 (22.4)	43.5 (24.0)	39.9 (23.0)	60.7 (22.8)	39.3 (22.7)	53.1 (24.0)	31.8 (21.5)	43.4 (24.2)	43.5 (23.4)	45.8 (24.5)
Score ≤ 50[b], n (%)		16 (44.4%)	74 (60.2%)	44 (67.7%)	53 (31.7%)	189 (67.3%)	127 (44.9%)	84 (79.2%)	75 (60.5%)	113 (61.7%)	775 (56.7%)
Missing		2	37	26	48	110	138	65	32	46	504
Zarit Burden Interview score, Mean (SD)	1340	20.0 (7.9)	22.3 (9.6)	22.0 (9.7)	16.5 (8.6)	21.4 (8.5)	17.9 (9.0)	22.7 (8.6)	24.0 (9.7)	22.5 (9.4)	20.6 (9.3)
Missing		2	37	28	50	119	141	69	35	51	532
GAINS score, Mean (SD)	1344	16.1 (6.1)	10.4 (6.7)	13.2 (5.8)	10.5 (6.4)	10.5 (6.3)	14.4 (6.4)	11.9 (6.0)	15.6 (6.1)	16.2 (6.5)	12.9 (6.7)
Missing		2	37	27	51	118	141	67	33	52	528
Willingness to Care score, Mean (SD)	1309	4.0 (0.8)	4.3 (0.7)	4.5 (0.6)	4.2 (0.7)	4.4 (0.6)	4.4 (0.7)	4.0 (0.7)	3.8 (0.6)	4.5 (0.5)	4.3 (0.7)
Missing		5	40	36	49	129	146	76	34	48	563
Ability to Care score, Mean (SD)	1304	26.1 (4.8)	28.0 (3.1)	28.6 (2.4)	26.5 (4.3)	28.2 (2.6)	27.4 (3.9)	28.2 (3.0)	27.2 (3.9)	28.2 (3.4)	27.7 (3.6)
Missing		5	41	37	48	129	145	75	35	53	568
Caregiver's relationship to care recipient, n (%)	1724										
Spouse/Partner		14 (37.8%)	16 (11.0%)	28 (35.0%)	36 (17.8%)	76 (21.3%)	165 (43.2%)	30 (19.6%)	89 (58.6%)	90 (41.7%)	544 (31.6%)
Mother or father		18 (48.6%)	98 (67.1%)	25 (31.2%)	104 (51.5%)	189 (53.1%)	114 (29.8%)	80 (52.3%)	29 (19.1%)	73 (33.8%)	730 (42.3%)
Mother-in-law or father-in-law		1 (2.7%)	3 (2.1%)	3 (3.8%)	10 (5.0%)	7 (2.0%)	11 (2.9%)	4 (2.6%)	1 (0.7%)	5 (2.3%)	45 (2.6%)
Daughter or son		1 (2.7%)	8 (5.5%)	15 (18.8%)	9 (4.5%)	42 (11.8%)	43 (11.3%)	10 (6.5%)	26 (17.1%)	26 (12.0%)	180 (10.4%)
Grandmother/ Grandfather		2 (5.4%)	2 (1.4%)	0 (0.0%)	19 (9.4%)	10 (2.8%)	3 (0.8%)	8 (5.2%)	0 (0.0%)	1 (0.5%)	45 (2.6%)
Sibling		0 (0.0%)	7 (4.8%)	3 (3.8%)	11 (5.4%)	11 (3.1%)	6 (1.6%)	6 (3.9%)	4 (2.6%)	7 (3.2%)	55 (3.2%)
Another family member		1 (2.7%)	1 (0.7%)	0 (0.0%)	5 (2.5%)	6 (1.7%)	12 (3.1%)	4 (2.6%)	0 (0.0%)	5 (2.3%)	34 (2.0%)
Friend		0 (0.0%)	4 (2.7%)	3 (3.8%)	1 (0.5%)	4 (1.1%)	9 (2.4%)	4 (2.6%)	0 (0.0%)	4 (1.9%)	29 (1.7%)
Acquaintance / Neighbour / Other non-relative		0 (0.0%)	7 (4.8%)	1 (1.2%)	2 (1.0%)	6 (1.7%)	9 (2.4%)	4 (2.6%)	1 (0.7%)	0 (0.0%)	30 (1.7%)
Other		0 (0.0%)	0 (0.0%)	2 (2.5%)	5 (2.5%)	5 (1.4%)	10 (2.6%)	3 (2.0%)	2 (1.3%)	5 (2.3%)	32 (1.9%)
Missing		1	14	11	13	35	39	18	4	13	148

Characteristic	N	Germany, N = 38	Greece, N = 160	Ireland, N = 91	Israel, N = 215	Italy, N = 391	Netherlands, N = 421	Poland, N = 171	Sweden, N = 156	UK, N = 229	Overall, N = 1,872
Care recipient's age, Median (SD)	1738	77.0 (11.4)	80.0 (18.2)	69.0 (22.4)	78.0 (19.4)	75.0 (20.8)	69.0 (19.6)	77.0 (17.7)	70.0 (19.5)	72.0 (20.2)	73.0 (19.9)
Missing		1	14	11	10	31	33	18	4	12	134
Care recipient's gender, n (%)	1738										
Female		16 (43.2%)	105 (71.9%)	31 (38.8%)	120 (58.5%)	205 (56.9%)	158 (40.7%)	95 (62.1%)	51 (33.6%)	90 (41.5%)	871 (50.1%)
Male		21 (56.8%)	40 (27.4%)	49 (61.3%)	84 (41.0%)	154 (42.8%)	227 (58.5%)	56 (36.6%)	100 (65.8%)	126 (58.1%)	857 (49.3%)
Prefer to self-describe		0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.5%)	0 (0.0%)	3 (0.8%)	1 (0.7%)	0 (0.0%)	0 (0.0%)	5 (0.3%)
Prefer not to say		0 (0.0%)	1 (0.7%)	0 (0.0%)	0 (0.0%)	1 (0.3%)	0 (0.0%)	1 (0.7%)	1 (0.7%)	1 (0.5%)	5 (0.3%)
Missing		1	14	11	10	31	33	18	4	12	134
Katz ADL Index score of the care recipient[c], Median (SD)	1713	3.0 (2.0)	3.0 (2.2)	3.0 (2.2)	4.0 (2.4)	1.0 (2.2)	4.0 (2.2)	2.0 (2.3)	4.0 (2.3)	2.0 (2.1)	3.0 (2.3)
Missing		1	14	11	13	40	43	19	4	14	159
Dependency level of the care recipient[d], n (%)	1713										
Independent		4 (10.8%)	27 (18.5%)	13 (16.2%)	68 (33.7%)	55 (15.7%)	111 (29.4%)	24 (15.8%)	55 (36.2%)	39 (18.1%)	396 (23.1%)
Partially Dependent		18 (48.6%)	56 (38.4%)	34 (42.5%)	64 (31.7%)	82 (23.4%)	137 (36.2%)	47 (30.9%)	50 (32.9%)	64 (29.8%)	552 (32.2%)
Dependent		15 (40.5%)	63 (43.2%)	33 (41.2%)	70 (34.7%)	214 (61.0%)	130 (34.4%)	81 (53.3%)	47 (30.9%)	112 (52.1%)	765 (44.7%)
Missing		1	14	11	13	40	43	19	4	14	159

WHO-5: The World Health Organisation Five Well-Being Index; ADL: Activities of Daily Living (eating, bathing, dressing, toileting, transferring, and continence).
[a] The range of score is from 0 (worst imaginable well-being) to 100 (highest imaginable well-being).
[b] WHO-5 score ≤ 50 indicates suboptimal well-being (Topp et al., 2015).
[c] Katz ADL index score of the care recipient as reported by the caregiver. The score ranges from 0 (dependence in all ADL) to 6 (total independence).
[d] Dependency level according to the Katz ADL index score of the care recipient as reported by the caregiver: Independent (score 6), Partially dependent (score 3–5), and Dependent (score 0-2) (Wallace & Shelkey, 2008).

The mean WHO-5 score, reflecting caregivers' well-being, was 45.8, with 56.7% of caregivers reporting suboptimal well-being (using a cut-off score of 50 (Topp et al., 2015)). Caregivers, on average, scored 20.6 on ZBI-12, indicating that they experience moderate to high burden, closer to the moderate end. The mean score of the GAINS scale was 12.9 out of a possible 30, with higher scores indicative of greater perceived gains from caregiving. Regarding the willingness and ability to care, the mean scores were 4.3 (max score = 5) and 27.7 (max score = 30), respectively (higher scores indicative of greater willingness and ability to care).

Caregiver participants were providing care for a parent (42.3%), partner (31.6%), child (10.4%), or sibling (3.2%), with the remaining (12.5%) providing care for other family

members and non-relatives. About half of participants' care recipients were females (50.1%), and their median age was 73 years, with the youngest in Ireland and the Netherlands (69y), Sweden (70y) and the UK (72y), and the oldest in Italy (75y), Germany and Poland (77y), Israel (78y) and Greece (80y). According to the Katz index (as reported by the caregiver participant), 76.9% of participants' care recipients were found to be at least partially dependent for ADL (Mdn = 3). With regards to the health conditions of participants' care recipients, the most reported condition by caregivers was other (32.5%), which represented conditions that did not fit into any other category (e.g., genetic disorders, physical disabilities, and mental health conditions). The next most reported condition was cognitive or memory impairment (29.9%), followed by hypertension (26.3%), heart disease (16.9%), diabetes (16.8%), stroke or cerebral vascular disease (16.0%), cancer (15.7%), high blood cholesterol (13.7%), cataracts (10.4%), and osteoarthritis or other rheumatism (10.3%). Each of the remaining conditions was reported in less than 10% of participants' care recipients. Also, 55.8% of caregivers reported providing care for a person with multiple chronic health conditions. Only 3.6% of caregivers reported that their care recipients were not diagnosed with any chronic disease, relating instead to care provided due to old age frailty or following an injury or acute illness. Table 2.A.2 in Appendix 2.A presents the chronic conditions of the care recipients as reported by the caregivers.

2.3.2.2. Characteristics of Care Recipient Participants

Table 2.3 presents the baseline characteristics of care recipient participants overall and by country. Care recipients had a median age of 55 years, with approximately three-quarters being female (77.1%). The majority of care recipient participants had at least a post-secondary education (77.1%) and were not employed (74.0%). More than half of the care recipients were married or in a partnership (58.5%) and were receiving care primarily from their spouses or partners (61.0%). On average, care recipients scored 40.7 on WHO-5, with 64.1% of them reporting suboptimal well-being (WHO-5 score $\leq$ 50). According to the Katz index, more than

two-thirds of surveyed care recipients (70.3%) were at least partially dependent for ADL, with a median Katz index score of 4. Furthermore, more than half of the care recipients (56.8%) had at least two coexisting chronic conditions. The most reported condition was other (48.6%), followed by hypertension (27.6%), osteoarthritis or other rheumatism (21.7%), cancer (18.9%), high blood cholesterol (18.6%), diabetes (17.6%), chronic lung disease (16.5%), and heart diseases (10.6%), with the remaining conditions contributing less than 10% each. The complete list of reported chronic health conditions and their prevalence among the care recipient sample is shown in Table 2.A.3 in Appendix 2.A.

Table 2.3. *Baseline Characteristics of Care Recipient Participants Overall and by Country*

Characteristic	N	Germany, N = 7	Greece, N = 37	Ireland, N = 26	Israel, N = 26	Italy, N = 67	Netherlands, N = 101	Poland, N = 46	Sweden, N = 26	UK, N = 66	Overall, N = 402
Age, Median (SD)	402	56.0 (14.5)	46.0 (12.7)	59.5 (14.2)	49.0 (17.8)	47.0 (15.8)	58.0 (12.6)	52.5 (14.9)	66.0 (15.5)	59.5 (12.9)	55.0 (14.9)
Gender, n (%)	402										
Female		6 (85.7%)	27 (73.0%)	19 (73.1%)	21 (80.8%)	46 (68.7%)	82 (81.2%)	33 (71.7%)	19 (73.1%)	57 (86.4%)	310 (77.1%)
Male		1 (14.3%)	9 (24.3%)	7 (26.9%)	3 (11.5%)	20 (29.9%)	19 (18.8%)	13 (28.3%)	6 (23.1%)	9 (13.6%)	87 (21.6%)
Non-binary/third gender		0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (3.8%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.2%)
Prefer to self-describe		0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (3.8%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.2%)
Prefer not to say		0 (0.0%)	1 (2.7%)	0 (0.0%)	0 (0.0%)	1 (1.5%)	0 (0.0%)	0 (0.0%)	1 (3.8%)	0 (0.0%)	3 (0.7%)
Education, n (%)	402										
Primary		1 (14.3%)	0 (0.0%)	1 (3.8%)	0 (0.0%)	2 (3.0%)	4 (4.0%)	1 (2.2%)	2 (7.7%)	2 (3.0%)	13 (3.2%)
Secondary		0 (0.0%)	13 (35.1%)	3 (11.5%)	5 (19.2%)	4 (6.0%)	18 (17.8%)	9 (19.6%)	5 (19.2%)	10 (15.2%)	67 (16.7%)
Post-secondary vocational education		4 (57.1%)	10 (27.0%)	8 (30.8%)	6 (23.1%)	35 (52.2%)	68 (67.3%)	14 (30.4%)	4 (15.4%)	22 (33.3%)	171 (42.5%)
Post-secondary academic education		1 (14.3%)	14 (37.8%)	14 (53.8%)	14 (53.8%)	26 (38.8%)	9 (8.9%)	19 (41.3%)	14 (53.8%)	28 (42.4%)	139 (34.6%)
Not listed or other		1 (14.3%)	0 (0.0%)	0 (0.0%)	1 (3.8%)	0 (0.0%)	2 (2.0%)	3 (6.5%)	1 (3.8%)	4 (6.1%)	12 (3.0%)
Employed = Yes, n (%)	400	0 (0.0%)	16 (43.2%)	6 (23.1%)	9 (34.6%)	28 (41.8%)	16 (16.0%)	14 (31.1%)	5 (19.2%)	10 (15.2%)	104 (26.0%)
Missing		0	0	0	0	0	1	1	0	0	2

Characteristic	N	Germany, N = 7	Greece, N = 37	Ireland, N = 26	Israel, N = 26	Italy, N = 67	Netherlands, N = 101	Poland, N = 46	Sweden, N = 26	UK, N = 66	Overall, N = 402
Marital status, n (%)	402										
Single		1 (14.3%)	12 (32.4%)	5 (19.2%)	9 (34.6%)	27 (40.3%)	10 (9.9%)	9 (19.6%)	2 (7.7%)	10 (15.2%)	85 (21.1%)
Married or in a partnership		4 (57.1%)	15 (40.5%)	16 (61.5%)	13 (50.0%)	33 (49.3%)	63 (62.4%)	29 (63.0%)	19 (73.1%)	43 (65.2%)	235 (58.5%)
Divorced		1 (14.3%)	7 (18.9%)	3 (11.5%)	4 (15.4%)	4 (6.0%)	10 (9.9%)	4 (8.7%)	3 (11.5%)	9 (13.6%)	45 (11.2%)
Widowed		1 (14.3%)	1 (2.7%)	1 (3.8%)	0 (0.0%)	3 (4.5%)	9 (8.9%)	4 (8.7%)	1 (3.8%)	3 (4.5%)	23 (5.7%)
Other		0 (0.0%)	2 (5.4%)	1 (3.8%)	0 (0.0%)	0 (0.0%)	9 (8.9%)	0 (0.0%)	1 (3.8%)	1 (1.5%)	14 (3.5%)
Main caregiver, n (%)	382										
Spouse/Partner		4 (57.1%)	18 (50.0%)	14 (58.3%)	12 (48.0%)	31 (47.7%)	67 (70.5%)	27 (61.4%)	19 (76.0%)	41 (67.2%)	233 (61.0%)
Child		2 (28.6%)	7 (19.4%)	1 (4.2%)	1 (4.0%)	9 (13.8%)	13 (13.7%)	3 (6.8%)	3 (12.0%)	8 (13.1%)	47 (12.3%)
Parent		0 (0.0%)	5 (13.9%)	3 (12.5%)	6 (24.0%)	14 (21.5%)	2 (2.1%)	7 (15.9%)	2 (8.0%)	4 (6.6%)	43 (11.3%)
Sibling		0 (0.0%)	2 (5.6%)	0 (0.0%)	1 (4.0%)	5 (7.7%)	3 (3.2%)	0 (0.0%)	1 (4.0%)	2 (3.3%)	14 (3.7%)
Nephew/Niece		0 (0.0%)	2 (5.6%)	0 (0.0%)	0 (0.0%)	1 (1.5%)	0 (0.0%)	2 (4.5%)	0 (0.0%)	0 (0.0%)	5 (1.3%)
Friend		0 (0.0%)	1 (2.8%)	2 (8.3%)	1 (4.0%)	0 (0.0%)	8 (8.4%)	1 (2.3%)	0 (0.0%)	3 (4.9%)	16 (4.2%)
Neighbour		0 (0.0%)	0 (0.0%)	2 (8.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (6.8%)	0 (0.0%)	0 (0.0%)	5 (1.3%)
Other		1 (14.3%)	1 (2.8%)	2 (8.3%)	4 (16.0%)	5 (7.7%)	2 (2.1%)	1 (2.3%)	0 (0.0%)	3 (4.9%)	19 (5.0%)
Missing		0	1	2	1	2	6	2	1	5	20
WHO-5 score[a], Mean (SD)	343	40.0 (28.3)	42.8 (24.3)	41.2 (20.8)	42.4 (22.8)	45.2 (21.8)	43.5 (22.4)	36.6 (22.6)	47.5 (24.3)	29.9 (22.3)	40.7 (23.0)
Score ≤ 50[b], n (%)		5 (71.4%)	21 (63.6%)	15 (65.2%)	13 (65.0%)	35 (58.3%)	47 (58.8%)	28 (68.3%)	13 (56.5%)	43 (76.8%)	220 (64.1%)
Missing		0	4	3	6	7	21	5	3	10	59
Katz ADL index score[c], Median (SD)	383	3.0 (1.1)	4.5 (2.2)	5.0 (2.1)	5.0 (1.6)	5.0 (2.1)	4.0 (1.9)	4.0 (2.1)	4.0 (2.1)	2.0 (1.9)	4.0 (2.0)
Missing		0	1	2	1	2	5	2	1	5	19
Dependency level[d], n (%)	383										
Independent		1 (14.3%)	14 (38.9%)	11 (45.8%)	10 (40.0%)	22 (33.8%)	25 (26.0%)	15 (34.1%)	8 (32.0%)	8 (13.1%)	114 (29.8%)
Partially Dependent		6 (85.7%)	12 (33.3%)	8 (33.3%)	12 (48.0%)	26 (40.0%)	46 (47.9%)	16 (36.4%)	9 (36.0%)	20 (32.8%)	155 (40.5%)
Dependent		0 (0.0%)	10 (27.8%)	5 (20.8%)	3 (12.0%)	17 (26.2%)	25 (26.0%)	13 (29.5%)	8 (32.0%)	33 (54.1%)	114 (29.8%)
Missing		0	1	2	1	2	5	2	1	5	19

WHO-5: The World Health Organisation Five Well-Being Index; ADL: Activities of Daily Living (eating, bathing, dressing, toileting, transferring, and continence).

[a] The range of score is from 0 (worst imaginable well-being) to 100 (highest imaginable well-being).

[b] WHO-5 score ≤ 50 indicates suboptimal well-being (Topp et al., 2015).

[c] The score ranges from 0 (dependence in all ADL) to 6 (total independence).

[d] Dependency level according to the Katz ADL index score: Independent (score 6), Partially dependent (score 3–5), and Dependent (score 0-2 [Wallace & Shelkey, 2008]).

2.4. Strengths and Limitations

Having enrolled 1,872 caregivers and 402 care recipients, the ENTWINE iCohort is one of the largest multinational cohort studies of informal care yet conducted. One strength of this study is that it was designed and implemented by researchers across a range of social and behavioural science disciplines with expertise in informal care. Perhaps the main strength of this study lies in its examination of a wide range of personal, interpersonal, psychological, social, economic, and geographic factors, both at baseline and follow-up. This allows the assessment of interrelationships between these variables cross-sectionally and longitudinally while controlling for many potential confounders, and thus we can address a broad spectrum of research questions related to informal care. Another strength of this study resides in its diverse sample of caregivers and care recipients from nine countries with differing long-term care systems and cultural norms and beliefs around informal care. Having such a diverse sample enhances the generalisability of the results whilst also enabling cross-country comparisons that can highlight both similarities and differences.

The present study shares the same limitations as other web-based cohort studies: low response rate, coverage bias, and non-response bias (Bethlehem, 2010). Despite the growing popularity of web-based surveys, debate continues about what can be considered an acceptable response rate (Fan & Yan, 2010; Fincham, 2008). Furthermore, web-based surveys generally achieve lower response rates than conventional surveys (Blumenberg & Barros, 2018; Millar & Dillman, 2011; Sinclair et al., 2012). The response rates achieved in the two baseline surveys were above 40%. Although lower than desired, these rates still exceeded the average for web-based surveys, as reported in previous studies (Shih & Xitao Fan, 2008). Several strategies were adopted to improve the response rate in the present study, including automatic login, sending two email reminders, and using simple web designs (Sammut et al., 2021). Nevertheless, one factor that might have affected the response rates was the survey fatigue associated with the

proliferation of (web-based) surveys that ensued at the time of the study due to the COVID-19 pandemic (de Koning et al., 2021). All things considered, we believe that the response rates achieved in the baseline surveys were satisfactory.

One of the main limitations of web-based surveys is the inherent coverage bias (Bethlehem, 2010). Web-based survey studies necessitate Internet access, and therefore those with no access to the Internet do not have the opportunity to participate in such studies. Clearly, the extent of the coverage bias in web-based studies is proportional to the share of the target population without Internet access (Sterrett et al., 2017). A suite of studies from the past decade shows that the coverage bias of web-based surveys has diminished in Europe as Internet access has become more widespread (Mohorko et al., 2013; Vicente & Reis, 2012). Now, Europe is one of the regions with the highest Internet penetration rates in the world. This is also true across all the countries studied, with Internet penetration rates ranging between 76%–94% (World Bank, 2022b). Therefore, it was assumed at the design stage that the participating countries have sufficiently high Internet penetration and are well suited for web-based studies.

Another important concern with web-based surveys is non-response bias (Wells et al., 2012). The risk of non-response bias in this study has likely been reduced by our efforts to improve the response rate. However, non-response bias in web-based surveys is not only a function of response rate but also of systematic differences between responders and non-responders (Stoop et al., 2010). Since the characteristics of non-respondents were unknown in this study, non-response bias could neither be estimated nor ruled out.

By design, and due to time and budget constraints, representative samples of caregivers and care recipients were not sought. However, best efforts were made to recruit diverse samples in order to capture the caregiving experiences of participants with different characteristics and care situations. Despite these efforts, females were overrepresented in both the caregiver and

care recipient samples. However, this overrepresentation of females is consistently observed in studies on informal care (Denham et al., 2020; Lethin et al., 2020; Oldenkamp, Hagedoorn, Stolk, et al., 2017) and reflects their actual dominance in informal care provision according to European statistics (Tur-Sinai et al., 2020; Zigante, 2018) and their greater willingness to participate in surveys in general (Johansson et al., 2019; Smith, 2008).

Another limitation of the present study is the smaller-than-expected sample size in some countries, which places limits on the types of analyses that could be performed in some cases. However, approaches such as pooling data (e.g., across countries) are being considered to provide sufficient statistical power to perform some analyses (e.g., subgroup analysis).

The timing of baseline data collection in the middle of the COVID-19 pandemic is both a strength and a limitation. Some participants might have experienced significant changes to their caregiving and care-receiving experiences due to COVID-19 restrictive measures. Several studies to date have shown how COVID-19 exacerbated caregivers' burdens and strains and negatively impacted their health, psychosocial, and financial outcomes (Beach et al., 2021; Bergmann & Wagner, 2021). Therefore, the COVID-19 situation and the countermeasures in place in each country at the time of data collection should be considered during data analysis and interpretation of findings. Despite the challenges, the timing of the study has also presented interesting opportunities to shed light on how caregivers' and care recipients' experiences have changed during a period of fluctuating infection rates and COVID-19 restrictions.

Finally, establishing and maintaining a longitudinal cohort of this size is costly, time-consuming, and resource-intensive. It was therefore difficult to follow the ENTWINE cohort beyond the 6-month follow-up period, thereby limiting the ability to examine longer-term patterns and outcomes within what is typically a dynamic caregiving experience.

2.5. Conclusion

The ENTWINE iCohort Study is a multinational longitudinal cohort study investigating the multidimensional experiences of informal caregivers and care recipients in nine countries with divergent care systems and cultural orientations toward caregiving. This cohort provides a fertile opportunity to examine a wide range of personal, interpersonal, psychological, social, economic, and geographic factors and how they influence caregiving outcomes, including caregiver perceived gains and burdens, well-being and quality of life. We believe that the data collected in this study hold great promise for advancing caregiving research internationally and will inform the development of caregiver interventions and services, as well as policies aiming to improve caregiving experiences and outcomes.

Appendices

2.A. Additional Tables

Table 2.A.1. *A Complete List of All Caregiver Organisations and Advocacy Groups Involved in the Recruitment of Participants*

Organisation	Country
Allianz pflegende Angehörige	Germany
Anziani e non solo	Italy
Associazione C'ENTRO	Italy
Associazione de Banfield	Italy
Federazione Alzheimer Italia	Italy
Caffè Alzheimer Falconara	Italy
Associazione PAzienti LIberi dalle Neoplasie UROteliali (PALINURO)	Italy
Diabete Italia Onlus	Italy
Associazione Parkinson Marche	Italy
Rete Caregiver	Italy
Associazione Errante	Italy
ASPI Groane	Italy
Caregivers Israel	Israel
Camoni - Friends for Health	Israel
Think Bodywhys	Ireland
Family caregivers Ireland	Ireland
Shine	Ireland
Saint Vincent de Paul Ireland	Ireland
Brain Tumour Ireland	Ireland
Care Alliance Ireland	Ireland
Chronic Pain Ireland	Ireland
Muscular Dystrophy Ireland	Ireland
Polio Survivors Ireland	Ireland
Inclusion Ireland	Ireland
Fundacja Hospicyjna	Poland
Stowarzyszenie Pomocy Psychologicznej Syntonia	Poland
Fundacja SM – walcz o siebie	Poland
Polskie Stowarzyszenie Diabetyków	Poland
Polskie Stowarzyszenie Pomocy Osobom z Chorobą Alzheimera	Poland
Fundacja W Związku Z Rakiem	Poland
Stowarzyszenie UNICORN	Poland
Fundacja ORCHidea	Poland
Niepelnosprawni.pl	Poland
Fundacja Instytut Praw Pacjenta i Edukacji Zdrowotnej	Poland
Punkt Wsparcia Seniora	Poland
Centrum Wsparcia – opiekunów nieformalnych i faktycznych	Poland
MantelzorgNL	the Netherlands
Zorgbelang	the Netherlands
Vilans	the Netherlands
Movisie	the Netherlands
Anhörigas riksförbund	Sweden

Organisation	Country
Hjärt-Lungfonden	Sweden
Diabetesfonden	Sweden
Prostatacancerförbundet	Sweden
Sarkomföreningen	Sweden
Alzheimerfonden	Sweden
Demenscentrum	Sweden
ParkinsonFonden	Sweden
AbbVie Sverigem	Sweden
ParkinsonFörbundet	Sweden
Anhörigstöd i Stockholms Län	Sweden
Parkinson Skåne	Sweden
Föreningen Balans Stockholm	Sweden
Svenska Ödemförbundet	Sweden
Mustaschkampen	Sweden
Alzheimerfonden	Sweden
Demensförbundet	Sweden
Anhörigas Riksförbund	Sweden
Svenska Diabetesförbundet	Sweden
Riksförbundet Balans	Sweden
Carers Wales	the United Kingdom
Carers Trust	the United Kingdom
Carers Officers Learning Improvement Network for Wales	the United Kingdom
Shared Lives	the United Kingdom
Carers Outreach Service	the United Kingdom
North East Wales Carers Information Service (NEWCIS)	the United Kingdom
Mencap Cymru	the United Kingdom
Age Cymru	the United Kingdom
Gwynedd Council	the United Kingdom
Centre for Ageing and Dementia Research	the United Kingdom
North Wales Social Care and Wellbeing Services Improvement Collaborative	the United Kingdom
Shared Care Scotland	the United Kingdom
Centre for International Research on Care	the United Kingdom
Labour and Equalities (CIRCLE)	the United Kingdom
Carers Federation	the United Kingdom
Join Dementia Research	the United Kingdom
Headway - The Brain Injury Association	the United Kingdom
The Brain Charity	the United Kingdom
MS Society UK	the United Kingdom
Breast Cancer UK	the United Kingdom

Table 2.A.2. *Care Recipient Condition(s) at Baseline as Reported by Their Caregiver*

Care Recipient Condition(s)[a]	N = 1,731
Cardiological condition (e.g., heart attack, myocardial infarction, coronary thrombosis, congestive heart failure, etc.) = Yes, n (%)	293 (16.9%)
Hypertension = Yes, n (%)	455 (26.3%)
High blood cholesterol = Yes, n (%)	238 (13.7%)
A stroke or cerebral vascular disease = Yes, n (%)	277 (16.0%)
Diabetes = Yes, n (%)	291 (16.8%)
Chronic lung disease (e.g., chronic bronchitis, emphysema, etc.) = Yes, n (%)	165 (9.5%)
Cancer = Yes, n (%)	271 (15.7%)
Gastrointestinal ulcer = Yes, n (%)	32 (1.8%)
Parkinson disease = Yes, n (%)	159 (9.2%)
Cataract(s) = Yes, n (%)	180 (10.4%)
Hip fracture = Yes, n (%)	91 (5.3%)
Other fractures = Yes, n (%)	78 (4.5%)
Cognitive or memory disorders (e.g., Alzheimer's disease, dementia, etc.) = Yes, n (%)	518 (29.9%)
Multiple sclerosis = Yes, n (%)	35 (2.0%)
Rheumatoid Arthritis = Yes, n (%)	95 (5.5%)
Osteoarthritis, or other rheumatism = Yes, n (%)	178 (10.3%)
Chronic kidney disease = Yes, n (%)	97 (5.6%)
Traumatic brain injury = Yes, n (%)	43 (2.5%)
HIV/AIDS = Yes, n (%)	2 (0.1%)
Other unspecified chronic condition(s) = Yes, n (%)	563 (32.5%)
Number of diagnosed chronic conditions(s), n (%)	
Care recipients with no diagnosed chronic condition	62 (3.6%)
Care recipients with one diagnosed chronic condition	703 (40.6%)
Care recipients with two or more diagnosed chronic conditions	966 (55.8%)

[a]The number of missing values for all items is 141.

Table 2.A.3. *Care recipient Condition(s) at Baseline*

Care Recipient Condition(s)[a]	N = 387
Cardiological condition (e.g., heart attack, myocardial infarction, coronary thrombosis, congestive heart failure, etc.) = Yes, n (%)	41 (10.6%)
Hypertension = Yes, n (%)	107 (27.6%)
High blood cholesterol = Yes, n (%)	72 (18.6%)
A stroke or cerebral vascular disease = Yes, n (%)	31 (8.0%)
Diabetes = Yes, n (%)	68 (17.6%)
Chronic lung disease (e.g., chronic bronchitis, emphysema, etc.) = Yes, n (%)	64 (16.5%)
Cancer = Yes, n (%)	73 (18.9%)
Gastrointestinal ulcer = Yes, n (%)	14 (3.6%)
Parkinson disease = Yes, n (%)	23 (5.9%)
Cataract(s) = Yes, n (%)	27 (7.0%)
Hip fracture = Yes, n (%)	8 (2.1%)
Other fractures = Yes, n (%)	20 (5.2%)
Cognitive or memory disorders (e.g., Alzheimer's disease, dementia, etc.) = Yes, n (%)	8 (2.1%)
Multiple sclerosis = Yes, n (%)	29 (7.5%)
Rheumatoid Arthritis = Yes, n (%)	28 (7.2%)
Osteoarthritis, or other rheumatism = Yes, n (%)	84 (21.7%)
Chronic kidney disease = Yes, n (%)	15 (3.9%)
Traumatic brain injury = Yes, n (%)	11 (2.8%)
HIV/AIDS = Yes, n (%)	5 (1.3%)
Other unspecified chronic condition(s) = Yes, n (%)	188 (48.6%)
Number of diagnosed chronic conditions(s), n (%)	
No diagnosed chronic condition	8 (2.1%)
One diagnosed chronic condition	159 (41.1%)
Two or more diagnosed chronic conditions	220 (56.8%)

[a]The number of missing values for all items is 15.

Chapter 3

Health and Labour Market Effects of Informal Care Provision: A Cross-Country Analysis

3. Health and Labour Market Effects of Informal Care Provision: A Cross-country Analysis†

Abstract: The ageing population poses significant challenges to long-term care (LTC) systems across Europe. Informal care has emerged as a potential remedy; however, its effects on caregivers' health and labour market participation remain a concern, with cross-country variations still poorly understood. Understanding these impacts is crucial for informed policymaking to address LTC needs. This study examines the health and labour market effects of informal caregiving across eight European countries and identifies the determinants of these outcomes. We utilised cross-sectional data from the ENTWINE iCohort Study for Germany, Greece, Ireland, Italy, the Netherlands, Poland, Sweden, and the United Kingdom. Health-related quality of life (HRQoL) was measured using the EuroQol five-level five-dimensional (EQ-5D-5L) instrument, while labour market impacts were assessed through the Caregiver Indirect and Informal Care Cost Assessment Questionnaire. EQ-5D utilities and VAS scores were compared with population norms. The determinants of EQ-5D utility were examined using a two-part model consisting of a logistic model and a generalised linear model (GLM) with a log link and gamma distribution. Determinants of EQ-VAS score were analysed using a GLM with a log link and quasi-Poisson distribution. A binary logistic regression analysed the reduction in working hours, while an ordinary least square regression assessed productivity. Caregivers across all countries exhibited lower EQ-5D utilities and VAS scores compared to the general population. Intensive caregiving, co-residence with care recipients, primary caregiving, and caring for highly dependent individuals were associated with poorer HRQoL outcomes. In contrast, caregivers' perceived ability to provide care and employment correlated with better outcomes. Respite care was associated with better HRQoL for intensive caregivers, whereas in-kind support services were linked to lower HRQoL among low-intensity caregivers. Significant cross-country variations were observed. Moreover, around 39% of employed caregivers reported reducing their working hours due to caregiving responsibilities. Employed caregivers also reported an average productivity loss of 32.26%. These labour market effects did not significantly vary across countries and were most pronounced among women, co-residing caregivers, and those providing intensive care. Our findings highlight the detrimental associations between informal caregiving and caregivers' health and labour market participation, varying by individual, caregiving, and contextual factors. Findings on these determinants can guide the development of targeted policies and services that address the diverse needs of caregivers across Europe.

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3.1. Introduction

Europe is currently witnessing a rapid ageing of its population. Within the EU, the old-age dependency ratio, which represents the proportion of individuals aged 65 years or older in relation to working-age individuals (aged 15–64), has surged from approximately 27.1% in 2012 to 33% in 2022 (Eurostat, 2023a). This demographic shift is expected to persist in the coming decades, resulting in an increased demand for LTC due to age-related disabilities, chronic illnesses, and frailty.

Numerous European countries have addressed this growing need for LTC by retrenching formal LTC provision and progressively relying on caregivers to provide additional support (Wieczorek et al., 2022). Simultaneously, long-term demographic and societal changes, such as declining fertility rates, heightened residential mobility, and increased female labour force participation, have contributed to a relative decrease in the availability of potential caregivers (Weaver & Weaver, 2014). Together, these trends have intensified the burden faced by the diminishing pool of caregivers (Ribeiro et al., 2022).

While numerous studies have linked informal caregiving to adverse health outcomes (Guerra-Martín et al., 2023; Hiel et al., 2015; Kaschowitz & Brandt, 2017), others have observed no significant effects (McMunn et al., 2009), identified negative impacts only in specific subgroups (Hansen et al., 2013), or even documented positive outcomes (Bom et al., 2019). This heterogeneity has prompted scholars to probe for underlying explanations. Some have pointed to study design limitations, particularly the inadequate consideration of factors that influence selection into the caregiving role (Sacco et al., 2022). Others have highlighted biases. One such bias is selection bias, where caregivers in poorer health are less likely to participate in studies or more likely to withdraw than their healthier counterparts (Janson et al., 2022). Another is reporting bias, in which caregivers might overestimate their self-reported

health due to skewed reference points. Spending time with a care recipient in poor health may lead caregivers to rate their own health more favourably, even though their health might be worsening (Di Novi et al., 2015).

Several hypotheses have also been proposed to explain this heterogeneity. One is the 'wear-and-tear hypothesis', which posits that the cumulative demands of continuous caregiving take a significant mental and physical toll over time (Townsend et al., 1989). This hypothesis is supported by studies indicating a progressive deterioration in caregivers' HRQoL over time (Oldenkamp, Hagedoorn, Wittek, et al., 2017; Pennington et al., 2024; Swinkels et al., 2019). In contrast, the 'adaptation hypothesis' suggests that while caregivers may experience initial negative health effects after assuming caregiving responsibilities, these effects level off or rebound as they adapt to the demands of the role and the worsening condition of the care recipient (Choi et al., 2012; Townsend et al., 1989).

Further still, some scholars have put forth the 'caring confers health benefit' hypothesis, which contends that caregiving can enhance caregivers' health and well-being (Thomas et al., 2015). Others adopt a more nuanced stance, arguing that while intensive caregiving is often linked to poor health outcomes (Vlachantoni et al., 2016), low-intensity caregiving may, in fact, improve the caregiver's health and well-being (Buyck et al., 2011). This perspective aligns with experimental evidence suggesting that caregiving's health impacts—whether positive or negative—are complex and contingent on various factors. These factors include the demographic and socioeconomic characteristics of the caregiver, the caregiving context, as well as cultural norms and welfare systems (Pearlin et al., 1990; Tolkacheva et al., 2011; Vlachantoni et al., 2013).

Disparities in caregivers' health outcomes across countries are another area of interest in the literature (Dujardin et al., 2011). Two main hypotheses have been proposed. The first

attributes these disparities to variations in caregiver support mechanisms, societal norms, and expectations regarding family involvement in caregiving (Bom & Stöckel, 2021). This hypothesis is supported by evidence of a negative North–South gradient, linking poorer health outcomes among caregivers in Southern European countries to reliance on families and limited public support characterising their LTC systems (Uccheddu et al., 2019). A similar trend has been observed in Eastern European countries (Brenna & Di Novi, 2016). The second hypothesis, also empirically supported, suggests consistent caregiving effects within subgroups of caregivers—such as co-residents or those providing high-intensity care—regardless of variations in LTC systems (Bom & Stöckel, 2021; Kaschowitz & Brandt, 2017). Given the wide range of influencing factors and their variability across countries, cross-country comparisons of caregiver health outcomes remain challenging (Bom & Stöckel, 2021; Hoefman et al., 2017).

While the health effects of informal caregiving have been extensively studied, insufficient attention has been given to these impacts in terms of HRQoL (Besser et al., 2024; Leech et al., 2023). HRQoL is a multidimensional health outcome that captures physical and mental health as well as functional status, providing a comprehensive understanding of the impact an experience—such as caregiving—can have on individuals (Bremmers et al., 2024). HRQoL can be measured using generic or condition-specific instruments (Whitehead & Ali, 2010). Although condition-specific instruments tend to be more responsive, generic instruments can translate varied health impacts into a single, common metric that facilitates comparisons across treatments, conditions, or populations (Vetter, 2010). Using these metrics for caregivers allows comparing their HRQoL to that of non-caregivers to estimate the disutility associated with caregiving (Leech et al., 2023).

Beyond its health implications, informal caregiving has long been recognised as having a negative impact on paid employment (Carmichael et al., 2008). This relationship is grounded in opportunity cost and time allocation theories: the time dedicated to caregiving often comes

at the expense of time that could otherwise be spent in paid work, imposing an opportunity cost in the form of forgone earnings (Bauer & Sousa-Poza, 2015). This trade-off between caregiving and labour supply can manifest at both the extensive and intensive margins (Keating et al., 2014; Van Houtven et al., 2013).

At the extensive margin, the literature suggests that informal care exerts a limited yet statistically significant effect on labour market participation (Leigh, 2010). At the intensive margin, caregiving seems to reduce working hours, though the magnitude of this effect remains generally modest (Bauer & Sousa-Poza, 2015). A less examined aspect is the potential decline in at-work productivity (presenteeism) among caregivers, a topic that has received comparatively little scholarly attention (Kolodziej et al., 2023).

The heterogeneity in these labour market effects appears to be shaped by individual and caregiving characteristics, particularly gender, co-residency, and the intensity of care provided (Keating et al., 2013). At the macro level, the availability of support services can also play a role in shaping labour force decisions, influencing the extent to which caregivers can reconcile employment with caregiving responsibilities (Vos et al., 2022). Variations in these macro-level factors across European countries are well-documented, often revealing a negative North–South gradient in generosity (Chiatti et al., 2018; Wieczorek et al., 2022). However, whether these differences translate into divergent labour market outcomes for caregivers across countries remains insufficiently explored.

This chapter aims to explore how informal caregiving is associated with health and labour market outcomes across a cohort of caregivers from eight European countries. It investigates the impact of informal caregiving on the HRQoL of caregivers, as measured by the EuroQol-5 Dimensions (EQ-5D) instrument. The investigation includes a detailed examination of HRQoL profiles of caregivers, comparing their HRQoL scores to those of the general

population and scrutinising the determinants associated with these scores. Regarding labour market outcomes, the study focuses on the intensive margin effects, particularly the reductions in working hours and at-work productivity, and thoroughly examines the factors that influence these outcomes.

By comparing the HRQoL of caregivers with that of the general population, this chapter brings into focus the health challenges caregivers face and uncovers potential health inequalities. Additionally, quantifying potential declines in caregivers' HRQoL will illustrate the extent of these health 'spillover effects' from caregiving, highlighting their relevance to policymaking. The chapter will also elucidate how individual, caregiving, and macro-level factors influence caregivers' health and labour market outcomes. These insights could support the development of targeted, effective support systems that benefit caregivers and enhance the sustainability of LTC systems.

3.2. Data and Methods

3.2.1. Data Source

The data used in this chapter comes from the baseline wave of the ENTWINE iCohort Study. The ENTWINE iCohort Study is a multinational longitudinal web-based cohort study that combines a two-wave panel survey (baseline + 6 months follow-up). The study was conducted between August 2020 and December 2021 in nine countries: Germany, Greece, Ireland, Israel, Italy, the Netherlands, Poland, Sweden, and the United Kingdom. Participants in this study were adult caregivers (≥18) who provided care to at least one adult individual with a chronic health condition, disability, or any other care need. Participants were recruited mainly through social media, newsletters, snowball sampling, and caregiver or patient organisations. The survey was administered in the local language and comprised five module sections: a core module and four additional modules, each addressing a specific theme related to informal

caregiving. Further details are available elsewhere (Elayan, Bei, et al., 2024; Morrison et al., 2022). We only used the data from the eight European countries for this analysis—Germany, Greece, Ireland, Italy, the Netherlands, Poland, Sweden, and the United Kingdom.

3.2.2. Dependent Variables

3.2.2.1. Quality of Life Assessment

To assess the HRQoL of caregivers, we utilised the five-level EuroQol five-dimensional instrument (EQ-5D-5L), a widely recognised and validated tool. The EQ-5D-5L is a generic, preference-based measure of HRQoL consisting of two parts: a descriptive system (the EQ-5D) and a visual analogue scale (EQ-VAS). The EQ-5D part includes five questions, each representing a health dimension (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). For each dimension, respondents indicate one of five levels of functioning (no problems, slight problems, moderate problems, severe problems, and unable/extreme problems), resulting in 3,125 possible health states. These health states are subsequently converted into index-based utility values by applying a country-specific valuation algorithm, where 0 represents a state equivalent to being dead, and 1 represents perfect health. Some severe health states may be considered worse than being dead, leading to negative utilities (Herdman et al., 2011).

We employed published country-specific value sets to calculate utilities from the EQ-5D questionnaires collected in our sample (Burström et al., 2020; Finch et al., 2022; Golicki et al., 2019; Hernández Alava et al., 2023; Hobbins, Barry, Kelleher, Shah, et al., 2018; Ludwig et al., 2018; van Hout et al., 2012). With the EQ-VAS, caregivers were asked to rate their overall perception of health on a scale with values ranging from 0 (worst imaginable health state) to 100 (best imaginable health state). The EQ-5D questionnaire was not administered to the Greek sample, as a Greek-validated digital version was unavailable during a significant portion of the

data collection period. One distinct advantage of the EQ-5D instrument is the availability of age- and sex-specific population norms for numerous countries. These norms allow us to benchmark the utility and VAS scores of caregivers in our sample against those of their respective general populations, enabling the assessment of potential HRQoL impairments associated with informal caregiving.

3.2.2.2. Labour Market Effects

The impact of caregiving on work was assessed using the Caregiver Indirect and Informal Care Cost Assessment Questionnaire (Landfeldt et al., 2019). This instrument is a standardised self-reported tool encompassing a total of 13 questions pertaining to caregivers' current and previous work status, productivity, and the provision of informal care. The tool has been employed in a wide range of research projects by academic institutions and organisations (The CIIQ, 2024). Our analysis focused on the effects at the intensive margin, specifically reductions in working hours and declines in at-work productivity attributable to the caregiving role. Reductions in working hours were categorised as a dichotomous variable (yes/no). The extent of self-reported productivity loss was measured on a scale from 0 to 10 and transformed into a proportion representing percentage work impairment, where 0 indicated no impairment (working as usual) and 100 represented a complete inability to work.

3.2.3. Independent Variables

The ENTWINE iCohort survey gathered comprehensive data on caregiver characteristics, including socio-demographics such as age, gender, educational attainment, employment status, and marital status. Information regarding household composition, location, and the caregiver's health status was also collected. The survey also assessed various aspects of the care situation, including whether the caregiver is the primary caregiver, whether the

caregiver resides with the care recipient, and the receipt of respite care, financial support, or in-kind caregiver support services such as information, training, and counselling.

The survey also covered other important dimensions of the care situation, including the intensity of caregiving, the perceived ability to provide care, and the dependency level of the care recipient. Caregiving intensity was measured using the Caregiver Indirect and Informal Care Cost Assessment Questionnaire (Landfeldt et al., 2019), which records the number of hours caregivers spent on four categories of informal care activities: (1) household activities, (2) personal care, (3) practical support, and (4) emotional support. The total hours of caregiving were capped at a weekly maximum of 126 hours to allow for a minimum of six hours for leisure and basic needs (e.g., personal care and sleep) (Huls et al., 2022).

Caregiver ability to provide care was assessed using the Willingness to Care scale developed by Abell (2001). This scale evaluated the willingness and capacity of caregivers to perform 30 caregiving tasks across three domains: emotional support, instrumental support (e.g., meal preparation, cleaning, and transportation to medical appointments), and physical or nursing support (e.g., changing bed sheets, bathing, and assisting with mobility). The Ability to Care (ATC) score was calculated for each caregiver by adding up the number of caregiving tasks they indicated they could perform, ranging from 0 (unable to perform any caregiving tasks) to 30 (able to perform all tasks).

Finally, the level of dependence of care recipients was assessed using the Katz Index of Independence in Activities of Daily Living (Katz, 1983; Wallace & Shelkey, 2008). This index measures the ability to perform activities of daily living (ADL), including bathing, dressing, toileting, transferring, continence, and feeding. The index produces a total score ranging from 0 to 6, with higher scores indicating greater ADL independence. The Katz Index was grouped

into three categories: independent (score of 6), partially dependent (scores of 3–5), and dependent (scores of 0–2).

3.2.4. Statistical Analyses

3.2.4.1. Descriptive Statistics

Descriptive summary statistics were calculated for socio-demographics, care situation, and outcome variables. Continuous variables were reported as means with standard deviations, while categorical variables were presented as frequencies with percentages. Mean, standard deviation (SD), median, and interquartile range were calculated for EQ-5D utilities and VAS scores by country and overall. The ten most frequently reported EQ-5D-5L health states, along with the least reported state, were identified and their corresponding mean utility values and VAS scores were reported.

The proportion of respondents who reported problems (levels 2–5) in each EQ-5D dimension was computed. Differences in these proportions across countries were examined using the χ^2 test. The Health State Density Curve (HSDC) and Health State Density Index (HSDI), proposed by Zamora et al. (2018), were utilised to examine EQ-5D health state patterns across different countries. The HSDC is a graphical representation of the frequency distribution of health states within a sample, wherein the cumulative frequency of reported health states is plotted against the cumulative frequency of the sample. The 45-degree diagonal line represents perfect equality, where each health state is proportionally represented in the sample. The degree to which the HSDC curve falls below the diagonal line indicates the extent of unevenness in the distribution of health states. Lower curves signify that a small number of states account for a relatively large share of the sample. The HSDI is computed as the area between the HSDC and the diagonal line of perfect equality, divided by the total area under the diagonal line. The HSDI ranges from 0 to 1, where 0 represents total inequality, and 1 represents total equality.

3.2.4.2. Comparison of HRQoL to General Population Norms

We used country-specific population-based norm reference values for the EQ-5D questionnaire to compare our sample's utilities and VAS scores to the general population. All population norms employed were derived using the same country-specific value sets used to calculate EQ-5D utilities in our sample (Golicki, 2021; Grochtdreis et al., 2019; Hobbins, Barry, Kelleher, & O'Neill, 2018; McNamara et al., 2023; Meregaglia et al., 2023; Szende et al., 2014; Teni et al., 2022). Deviations from reference norms for utilities and VAS scores were calculated by subtracting the general population's average scores—matched by age group and gender—from caregivers' corresponding scores. Negative values indicated worse HRQoL than counterparts from the general population. A bootstrapped paired t-test (100,000 permutations) was used to assess whether the sample-derived means of EQ-5D utility and VAS score for each country differed significantly from the corresponding means of age- and gender-matched population norms. The nonparametric one-sample Wilcoxon signed rank test was also performed to validate the results. Due to the absence of published population norms for Ireland, responses from Irish caregivers were excluded from this analysis. All analyses were performed using the R software version 4.4.1 and Stata/SE 18.0 software (R Core Team, 2024; StataCorp, 2023).

3.2.4.3. Identification of the Determinants of the EQ-5D Utility and VAS Score

EQ-5D utility and VAS score data often violate the normality assumption, typically exhibiting highly skewed distributions (Starkie et al., 2011). Generalised Linear Models (GLMs) are particularly well-suited for such data, as they provide the flexibility to specify appropriate mean and variance functions based on the fit of the data (S. Murphy et al., 2018). Several tests were conducted to identify the most appropriate models for analysing the determinants. The modified Park test was used to determine the most suitable variance function

(i.e., the distributional family) (Glick et al., 2014; Manning & Mullahy, 2001), while the Pearson correlation test, the Pregibon link test, and the modified Hosmer-Lemeshow test were employed to identify the mean function (i.e., the link function) (Hosmer & Lemeshow, 2000; Pearson & Please, 1975; Pregibon, 1980). These tests indicated that a Poisson distribution with a log link function was the most appropriate choice for analysing VAS scores. To relax the strict equidispersion assumption of the Poisson model, we opted for a quasi-Poisson model (McCullagh, 1989).

EQ-5D utility values were transformed to the EQ-5D disutility scale (1− EQ-5D utility), a common approach in the literature to ensure non-negative values such that commonly applied distributions could be fit (McCaffrey et al., 2016; Sharma et al., 2019; Starkie et al., 2011). The determinants of EQ-5D disutilities were examined using a two-part model approach to accommodate excess zero values corresponding to full health status (Starkie et al., 2011; Su et al., 2022). The first part of the model used logistic regression to estimate the probability of non-zero values. The appropriate GLM for the second part of the model was identified following the same procedure described earlier, with the results indicating that a Gamma GLM with a log link function was the most suitable model for this analysis.

We investigated several potential determinants that could impact caregivers' HRQoL, including caregiver characteristics and the care situation. Caregiver characteristics comprised age (18–44, 45–54, 55–64, 65+), gender (male, female), educational attainment (primary or secondary education, post-secondary education), marital status (single; married or partnered; divorced, widowed, or other), employment status (not employed, employed part-time, employed full-time), and health status (whether diagnosed with at least one health condition). Care situation characteristics included primary caregiving responsibility (yes/no), co-residence with the care recipient (yes/no), presence of children under 18 in the household (yes/no), urbanicity (urban, rural), caregiving intensity (<20 hours, 20–50 hours, >50 hours per week),

total duration of caregiving, perceived ability to care, and care recipient's dependency level (independent, partially dependent, dependent). Additional characteristics included the country of residence as well as the receipt of support services, i.e., respite care, financial support, and in-kind support. Interaction effects were investigated for caregiving intensity with co-residency, primary caregiving, and service utilisation.

3.2.4.4. Identification of the Determinants of Labour Market Effects

The determinants of the labour market effects associated with informal caregiving were investigated among the subsample of employed caregivers aged below 65. An indicator variable was constructed to reduced working hours, and the probability of doing so was investigated using a binary logistic regression. The determinants of at-work productivity loss were explored using ordinary least square regression. Germany was excluded from the analysis of the labour market effects due to small sample size.

3.3. Results

3.3.1. Sample Characteristics

The total sample for the present study comprised 1,657 caregiver participants. Table 3.1 summarises the participants' sociodemographics and care situation characteristics by country. The average age of the sample was 54.55 years, with the youngest participants found in Poland (49.94 years) and the oldest in Sweden (59.45 years). Approximately one-third of participants (32%) were aged between 55 and 64, while the majority were female (88%). Nearly two-thirds of participants (67%) were married or in a partnership, with some variations across countries, ranging from 54% in Greece to 74% in Sweden. A large portion of participants (82%) had post-secondary education (i.e., tertiary vocational or academic qualifications). Half of the participants (50%) were employed; however, lower percentages were observed in Ireland (33%) and the UK (40%). The mean weekly working hours among employed caregivers amounted to

30.60, with marginally fewer hours observed in the Netherlands (26.77 hrs) and the UK (27.73 hrs).

Table 3.1. *Characteristics of Caregivers and Care Situation Overall and by Country*

Characteristic	N	Germany, N = 38	Greece, N = 160	Ireland, N = 91	Italy, N = 391	Netherlands, N = 421	Poland, N = 171	Sweden, N = 156	UK, N = 229	Overall, N = 1,657
Age, Mean (SD)	1,657	57.42 (13.52)	51.66 (11.46)	54.90 (11.16)	51.68 (11.74)	56.45 (11.06)	49.94 (12.92)	59.45 (13.24)	57.51 (12.41)	54.55 (12.30)
Age, n (%)	1,657									
18–44		6 (16%)	38 (24%)	17 (19%)	102 (26%)	46 (11%)	58 (34%)	20 (13%)	34 (15%)	321 (19%)
45–54		5 (13%)	56 (35%)	26 (29%)	113 (29%)	129 (31%)	50 (29%)	29 (19%)	49 (21%)	457 (28%)
55–64		16 (42%)	53 (33%)	31 (34%)	125 (32%)	155 (37%)	39 (23%)	41 (26%)	77 (34%)	537 (32%)
65+		11 (29%)	13 (8%)	17 (19%)	51 (13%)	91 (22%)	24 (14%)	66 (42%)	69 (30%)	342 (21%)
Gender, n (%)	1,657									
Female		28 (74%)	138 (86%)	81 (89%)	336 (86%)	385 (91%)	154 (90%)	137 (88%)	205 (90%)	1,464 (88%)
Male		10 (26%)	22 (14%)	10 (11%)	55 (14%)	36 (9%)	17 (10%)	19 (12%)	24 (10%)	193 (12%)
Marital status, n (%)	1,657									
Single		6 (16%)	36 (22%)	14 (15%)	104 (27%)	38 (9%)	39 (23%)	12 (8%)	22 (10%)	271 (16%)
Married or partnered		26 (68%)	87 (54%)	65 (71%)	243 (62%)	301 (71%)	102 (60%)	115 (74%)	168 (73%)	1,107 (67%)
Divorced, widowed or other		6 (16%)	37 (23%)	12 (13%)	44 (11%)	82 (19%)	30 (18%)	29 (19%)	39 (17%)	279 (17%)
Education, n (%)	1,657									
Primary or secondary education		5 (13%)	44 (28%)	18 (20%)	33 (8%)	81 (19%)	32 (19%)	36 (23%)	41 (18%)	290 (18%)
Post-secondary education		33 (87%)	116 (72%)	73 (80%)	358 (92%)	340 (81%)	139 (81%)	120 (77%)	188 (82%)	1,367 (82%)
Employment status, n (%)	1,608									
Not employed		17 (46%)	67 (43%)	58 (67%)	186 (49%)	187 (46%)	65 (41%)	88 (56%)	135 (60%)	803 (50%)
Part-time		9 (24%)	28 (18%)	15 (17%)	66 (17%)	153 (38%)	23 (14%)	26 (17%)	49 (22%)	369 (23%)
Full-time		11 (30%)	61 (39%)	14 (16%)	129 (34%)	66 (16%)	72 (45%)	42 (27%)	41 (18%)	436 (27%)
Hours of work, Mean (SD)	805	31.00 (11.21)	31.54 (15.21)	29.24 (19.00)	32.37 (10.85)	26.77 (10.80)	35.91 (14.45)	33.43 (11.31)	27.73 (12.61)	30.60 (12.78)
Home location, n (%)	1,657									
Central city/area		15 (39%)	74 (46%)	10 (11%)	139 (36%)	94 (22%)	74 (43%)	63 (40%)	32 (14%)	501 (30%)
Peripheral/rural area		23 (61%)	86 (54%)	81 (89%)	252 (64%)	327 (78%)	97 (57%)	93 (60%)	197 (86%)	1,156 (70%)
Diagnosed with a health condition, n (%)	1,558									
No		14 (38%)	97 (64%)	38 (46%)	216 (59%)	197 (50%)	94 (61%)	73 (48%)	106 (48%)	835 (54%)
Yes		23 (62%)	55 (36%)	45 (54%)	152 (41%)	194 (50%)	60 (39%)	80 (52%)	114 (52%)	723 (46%)
Children at home, n (%)	1,640									
No		34 (89%)	94 (59%)	41 (45%)	233 (60%)	254 (61%)	104 (63%)	116 (74%)	159 (70%)	1,035 (63%)
Yes		4 (11%)	66 (41%)	50 (55%)	155 (40%)	161 (39%)	62 (37%)	40 (26%)	67 (30%)	605 (37%)
Primary caregiver, n (%)	1,395									
No		8 (22%)	36 (26%)	5 (7%)	68 (21%)	40 (12%)	23 (18%)	13 (9%)	21 (10%)	214 (15%)
Yes		29 (78%)	103 (74%)	69 (93%)	257 (79%)	307 (88%)	107 (82%)	130 (91%)	179 (90%)	1,181 (85%)
Coresident caregiver, n (%)	1,522									
No		19 (51%)	66 (45%)	19 (24%)	117 (33%)	183 (48%)	60 (39%)	49 (32%)	64 (30%)	577 (38%)
Yes		18 (49%)	80 (55%)	61 (76%)	239 (67%)	199 (52%)	93 (61%)	103 (68%)	152 (70%)	945 (62%)
Care intensity (hours per week), Mean (SD)	1,406	59.84 (41.35)	48.25 (34.75)	71.72 (40.79)	64.60 (41.22)	38.43 (35.22)	62.08 (39.59)	41.49 (32.57)	61.69 (39.73)	53.73 (39.65)

Characteristic	N	Germany, N = 38	Greece, N = 160	Ireland, N = 91	Italy, N = 391	Netherlands, N = 421	Poland, N = 171	Sweden, N = 156	UK, N = 229	Overall, N = 1,657
Care intensity (hours per week), n (%)	1,406									
Below 20		8 (22%)	32 (23%)	7 (9%)	58 (18%)	143 (41%)	21 (16%)	33 (23%)	36 (18%)	338 (24%)
20–50		10 (27%)	56 (41%)	21 (28%)	88 (27%)	117 (33%)	38 (29%)	66 (47%)	57 (28%)	453 (32%)
Above 50		19 (51%)	50 (36%)	47 (63%)	183 (56%)	92 (26%)	72 (55%)	42 (30%)	110 (54%)	615 (44%)
Total months of caregiving, Mean (SD)	1,500	53.28 (66.92)	80.64 (107.56)	105.64 (113.68)	96.97 (107.87)	101.84 (99.29)	70.96 (78.62)	76.84 (88.88)	100.72 (110.74)	91.91 (101.84)
[a] Dependency level of the care recipient, n (%)	1,511									
Independent		4 (11%)	27 (18%)	13 (16%)	55 (16%)	111 (29%)	24 (16%)	55 (36%)	39 (18%)	328 (22%)
Partially Dependent		18 (49%)	56 (38%)	34 (42%)	82 (23%)	137 (36%)	47 (31%)	50 (33%)	64 (30%)	488 (32%)
Dependent		15 (41%)	63 (43%)	33 (41%)	214 (61%)	130 (34%)	81 (53%)	47 (31%)	112 (52%)	695 (46%)
[b] Ability to care score, Mean (SD)	1,137	26.09 (4.82)	27.97 (3.10)	28.61 (2.43)	28.19 (2.63)	27.42 (3.94)	28.17 (3.01)	27.24 (3.94)	28.20 (3.37)	27.84 (3.42)
Financial support, n (%)	1,322									
No		21 (57%)	122 (90%)	40 (55%)	258 (83%)	287 (91%)	105 (85%)	127 (95%)	131 (69%)	1,091 (83%)
Yes		16 (43%)	13 (10%)	33 (45%)	53 (17%)	30 (9%)	19 (15%)	7 (5%)	60 (31%)	231 (17%)
Respite care, n (%)	1,317									
No		24 (65%)	118 (86%)	61 (84%)	267 (85%)	254 (83%)	114 (91%)	109 (81%)	168 (88%)	1,115 (85%)
Yes		13 (35%)	19 (14%)	12 (16%)	46 (15%)	53 (17%)	11 (9%)	25 (19%)	23 (12%)	202 (15%)
In-kind services, n (%)	1,336									
No		19 (51%)	70 (51%)	48 (65%)	189 (60%)	197 (61%)	67 (54%)	59 (44%)	93 (48%)	742 (56%)
Yes		18 (49%)	67 (49%)	26 (35%)	125 (40%)	124 (39%)	58 (46%)	75 (56%)	101 (52%)	594 (44%)

Note. SD = Standard Deviation; Sample sizes vary due to missing data and the applicability of certain variables only to specific subgroups.
[a] Dependency level based on the Katz ADL index score as reported by the caregiver: Independent (score 6), Partially dependent (score 3–5), and Dependent (score 0–2) (Wallace & Shelkey, 2008).
[b] Ability to Care Scale (Abell, 2001)

Nearly one-third of participants (30%) lived in central areas, while just under half (46%) reported being diagnosed with at least one health condition. Additionally, around one-third (37%) had a child residing in their household. The majority of participants (85%) identified as the primary caregiver for their care recipient, and nearly two-thirds (62%) reported living with their care recipient. On average, participants spent 53.73 hours per week on caregiving, with a mean total caregiving duration of 91.91 months.

Regarding the ability to care, the mean score was 27.84. Based on the Katz index (as reported by the caregivers), 78% of their care recipients were identified as being at least partially dependent on ADLs. Approximately 17% of participants reported receiving financial support, while 15% reported obtaining respite services, and just under half (44%) reported accessing in-kind caregiver support services.

3.3.2. Health-Related Quality of Life (HRQoL)

3.3.2.1. Descriptive Statistics

Table 3.2 presents a summary of EQ-5D utility and VAS score by country. The mean EQ-5D utility for all countries was 0.76 (SD: 0.23), with a median value of 0.82 (interquartile range: 0.69–0.91). Swedish and Polish caregivers had the highest mean utility (0.84), whereas Italian caregivers had the lowest (0.69). The mean VAS score across all countries was 65.46 (SD: 21.10), while the median score was 70 (interquartile range: 50–80). The Netherlands exhibited the highest mean VAS score (68.54), and Poland had the lowest (60.22).

Table 3.2. *Summary of EQ-5D Utility and VAS Score by Country*

Characteristic	N	Germany, N = 38	Ireland, N = 91	Italy, N = 391	Netherlands, N = 421	Poland, N = 171	Sweden, N = 156	UK, N = 229	Overall, N = 1,497
EQ-5D Utility	1,050								
Mean (SD)		0.80 (0.20)	0.74 (0.25)	0.69 (0.33)	0.78 (0.16)	0.84 (0.16)	0.84 (0.13)	0.72 (0.21)	0.76 (0.23)
Median (IQR)		0.86 (0.73, 0.94)	0.80 (0.70, 0.91)	0.82 (0.56, 0.91)	0.81 (0.71, 0.87)	0.90 (0.79, 0.95)	0.88 (0.77, 0.93)	0.74 (0.64, 0.87)	0.82 (0.69, 0.91)
Range		0.10, 1.00	-0.20, 1.00	-0.57, 1.00	0.21, 1.00	0.36, 1.00	0.44, 0.98	-0.21, 0.99	-0.57, 1.00
Missing		4	27	121	144	66	36	49	447
EQ-VAS Score	942								
Mean (SD)		66.22 (15.71)	67.88 (16.53)	63.24 (23.68)	68.54 (20.14)	60.22 (18.91)	63.37 (21.80)	67.29 (21.16)	65.46 (21.10)
Median (IQR)		67 (58.50, 80.00)	70 (51.75, 80.00)	70 (50.00, 80.00)	70 (60.00, 80.00)	60 (50.00, 71.00)	70 (50.00, 80.00)	70 (58.00, 80.00)	70 (50.00, 80.00)
Range		36.00, 90.00	21.00, 96.00	0.00, 100.00	0.00, 100.00	0.00, 100.00	0.00, 100.00	0.00, 100.00	0.00, 100.00
Missing		6	33	167	170	73	44	62	555

Of the 3,125 potential health states in the EQ-5D-5L instrument, 276 (8.8%) were reported by at least one study participant. Table 3.3 depicts the ten most frequently reported health states and the least reported health state. The ten most frequently reported health states accounted for approximately 47% of the sample. The most common health state, '11111' (no problems), was reported by 11.0% of participants. The second most frequent health state (7.8%) was '11122' (slight pain/discomfort and slight anxiety/depression), followed by '11112' (slight anxiety/depression) at 7.3%. The least common health state was '55555', indicating the highest level of problems in each dimension.

Table 3.3. *Prevalence of the Ten Most Frequently Reported Health States and the Least Reported Health State*

State	Frequency (%)	Cumulative frequency (%)	Mean EQ-5D Utility	Mean EQ-5D VAS Score
11111	115 (10.95)	115 (10.95)	1.00	82.04
11122	82 (7.81)	197 (18.76)	0.87	74.30
11112	77 (7.33)	274 (26.10)	0.92	80.99
11121	69 (6.57)	343 (32.67)	0.90	75.68
11123	51 (4.86)	394 (37.52)	0.82	65.28
11113	26 (2.48)	420 (40.00)	0.85	62.68
11131	20 (1.9)	440 (41.90)	0.89	63.47
21122	19 (1.81)	459 (43.71)	0.80	68.67
11223	17 (1.62)	476 (45.33)	0.79	60.71
11133	16 (1.52)	492 (46.86)	0.76	60.60
…				
55555	1 (0.1)	1050 (100.00)	-0.57	10.00

The distribution of EQ-5D health states varied across countries. The HSDC revealed that caregivers in the Netherlands and the UK had the most concentrated health states (i.e., the least evenly distributed), whereas the curve for German caregivers was the least concentrated (i.e., the most evenly distributed). Although the HSDCs for Swedish and Italian caregivers were nearly identical, the former demonstrated less concentration in the most frequent health states, resulting in a larger HSDI. The curves for Polish and Irish caregivers were virtually indistinguishable (see Figure 3.1).

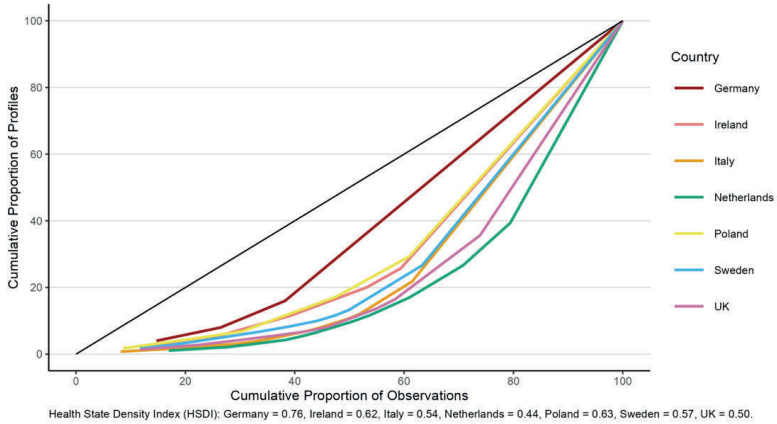


Figure 3.1. *Health State Density Curve (HSDC)*

Of the five EQ-5D dimensions, problems were most frequently reported for pain/discomfort (72%), followed by anxiety/depression (68%), usual activities (44%), mobility (34%), and self-care (14%). For all EQ-5D dimensions, significant differences between countries emerged in the proportion of respondents reporting problems (see Figure 3.2).

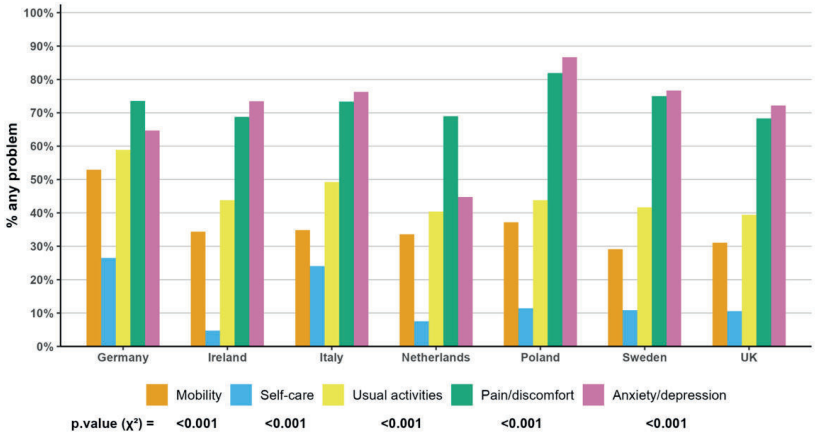


Figure 3.2. *Frequency of Any Problems (Levels 2–5) in EQ-5D-5L Dimensions by Country*

3.3.2.2. EQ-5D Utility and VAS Score Among Caregivers Versus Population Norms

Figure 3.3 compares the mean EQ-5D utility between caregivers and the general population in their respective countries, adjusted for age and sex. On average, caregivers exhibited a reduction of -0.12 (SD: 0.23) in EQ-5D utility compared to the general population. Statistically significant reductions in EQ-5D utility were observed among caregivers in all countries compared to their respective population norms, as determined by the bootstrapped paired t-test and validated by the one-sample Wilcoxon signed rank test. The average decline ranged from 0.063 in Germany to 0.223 in Italy. Figure 3.4 illustrates the differences in EQ-5D utility between caregivers and the general population, stratified by caregiving intensity and country. Across all countries, greater declines in EQ-5D utility were observed with increasing levels of caregiving intensity. Caregivers providing low-intensity care in Italy and the Netherlands demonstrated significantly lower utility values than population norms. High-intensity caregivers showed significantly lower utility values across all countries, while those providing moderate-intensity care experienced significant declines in Italy, the Netherlands, Sweden, and the UK.

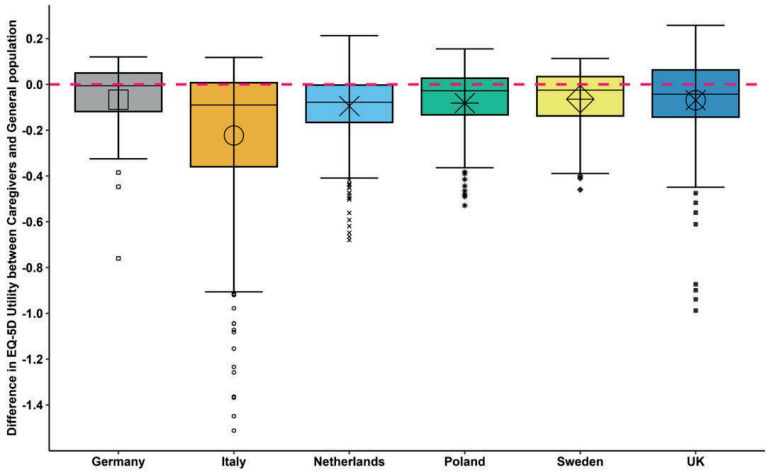
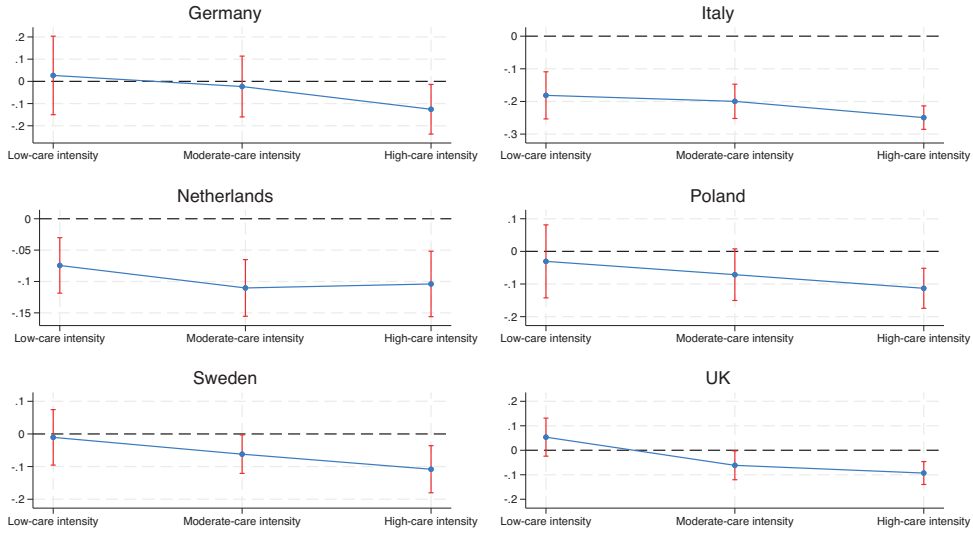


Figure 3.3. *Difference in EQ-5D Utility Between Caregivers and the General Population Norm Matched by Gender and Age, and Stratified by Country*



Note. The y-axis represents the difference in EQ-5D-5L utilities. The dotted line at y = 0 indicates no difference in utilities.
The x-axis represents care intensity: 'Low-care intensity' (< 20 hours), 'Moderate-care intensity' (20-50 hours), and 'High-care intensity' (> 50 hours).

Figure 3.4. *Difference in EQ-5D Utility Between Caregivers and the General Population by Care Intensity and Country*

A similar trend was observed when comparing caregivers' VAS scores to the population norms (see Figure 3.5). On average, caregivers across all countries reported a reduction of -13.62 (SD: 21.34) in VAS score compared to the general population, adjusted for age and sex. Across all countries, caregivers reported statistically significant lower VAS scores compared to their respective general populations. The difference in VAS score varied from a 6-point discrepancy in Germany to an approximately 18-point discrepancy in Italy. As with EQ-5D utilities, caregiving intensity was negatively correlated with VAS scores across all countries (see Figure 3.6). Low-intensity caregiving was associated with significant reductions in VAS scores in Italy and the Netherlands, while high-intensity caregiving consistently resulted in lower VAS scores across all countries. Moderate-intensity caregiving led to significant declines in VAS scores in all countries except Germany.

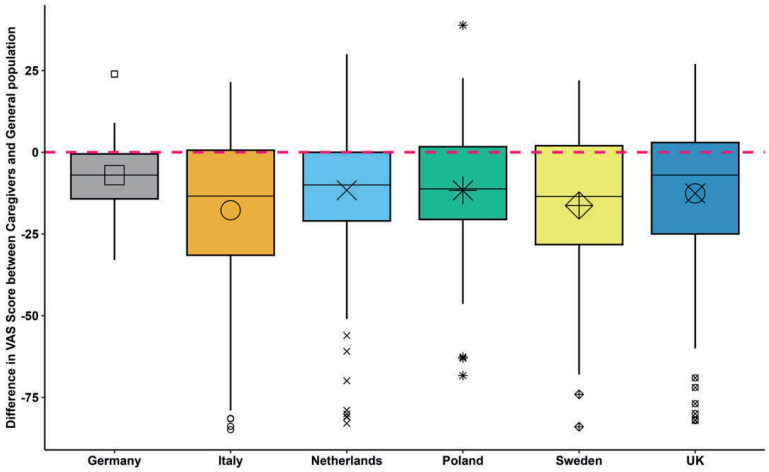
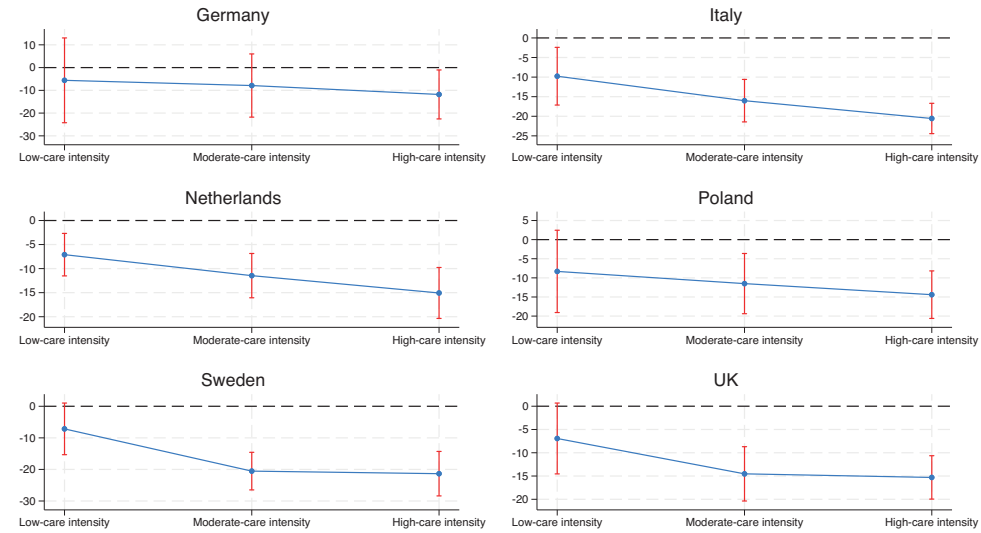


Figure 3.5. *Difference in EQ-VAS Score Between Caregivers and the General Population Norm Matched by Gender and Age, and Stratified by Country*



Note. The y-axis represents the difference in EQ-VAS scores. The dotted line at y = 0 indicates no difference in VAS scores.
The x-axis represents care intensity: 'Low-care intensity' (< 20 hours), 'Moderate-care intensity' (20-50 hours), and 'High-care intensity' (> 50 hours).

Figure 3.6. *Difference in EQ-VAS Score Between Caregivers and the General Population by Care Intensity and Country*

3.3.2.3. The Determinants of Health-Related Quality of Life (HRQoL)

Table 3.4 displays the average marginal effects (AME) for EQ-5D disutility from the two-part model. As expected, caregivers who self-reported at least one health condition experienced significantly higher disutility. Higher perceived caregiving ability was correlated with decreased disutility, while greater caregiving intensity corresponded to higher disutility. Employed caregivers—either working full or part-time—reported lower disutility than their non-employed counterparts. In contrast, primary caregivers were more likely to report higher disutility compared to non-primary caregivers. The duration of caregiving was not significantly associated with disutility. The interaction between primary caregiving and caregiving intensity had a marginally significant positive association with disutility for low-care intensity (p-value = .056; 95% CI = [-.001, .060]) (see Figure 3.7). Providing care to individuals dependent on all ADLs was positively associated with disutility. Notably, receiving financial support, respite

care, and in-kind support services was not significantly associated with caregivers' disutilities. However, the interaction between caregiving intensity and receiving respite care was significantly associated with lower disutility for the high-care intensity group (see Figure 3.8), whereas the interaction with in-kind services had a significant positive association for the low-care intensity group (see Figure 3.9). Furthermore, we observed notable differences in EQ-5D disutility across countries. Compared to the Netherlands, Italy exhibited the highest disutility, while Poland and Sweden exhibited the lowest.

Table 3.4. *Average Marginal Effects for EQ-5D VAS Score and EQ-5D-5L Disutility*

	EQ-VAS Score	EQ-5D Disutility
	AME (SE)	AME (SE)
Age (ref: 18–44)		
45–54	-4.156* (2.044)	0.015 (0.019)
55–64	-1.818 (2.036)	-0.001 (0.018)
65+	1.205 (2.472)	-0.028 (0.021)
Gender (ref: Female)		
Male	0.541 (1.926)	-0.015 (0.016)
Marital status (ref: Single)		
Married or partnered	2.023 (1.959)	-0.004 (0.019)
Divorced, widowed or other	0.136 (2.409)	0.035 (0.025)
Education level (ref: Primary or secondary education)		
Post-secondary education	0.445 (1.715)	-0.009 (0.016)
Employment status (ref: Not employed)		
Part-time	1.235 (1.670)	-0.029* (0.014)
Full-time	3.611* (1.723)	-0.047** (0.014)
Children at home (ref: No)		
Yes	-5.194*** (1.497)	0.001 (0.013)
Home location (ref: Central city/area)		
Peripheral/rural area	-1.685 (1.416)	0.018 (0.012)
Diagnosed with a health condition (ref: No)		
Yes	-11.106*** (1.250)	0.113*** (0.011)
Primary caregiver (ref: No)		
Yes	-2.213 (1.892)	0.032* (0.015)
Co-resident caregiver (ref: No)		
Yes	-3.284* (1.549)	0.024 (0.013)
Hours of care per week (ref: Below 20)		
20–50	-4.459* (1.751)	0.039** (0.014)
Above 50	-4.936* (1.957)	0.049** (0.016)
Total months of caregiving	-0.006 (0.007)	-0.000 (0.000)
CR's dependency level (ref; Independent)		
Partially Dependent	-0.713 (1.710)	0.024 (0.014)
Dependent	-2.451 (1.715)	0.036* (0.015)

	EQ-VAS Score	EQ-5D Disutility
	AME (SE)	AME (SE)
Ability to care (Abel scale)	0.444* (0.191)	-0.004* (0.002)
Financial support (ref: No)		
Yes	3.261 (1.811)	0.001 (0.016)
Respite care (ref: No)		
Yes	1.647 (1.777)	-0.021 (0.014)
In-kind services (ref: No)		
Yes	0.381 (1.272)	0.015 (0.011)
Country of residence (ref: Netherlands)		
UK	-2.257 (2.138)	0.023 (0.016)
Sweden	-7.121** (2.325)	-0.068*** (0.014)
Poland	-10.879*** (2.479)	-0.061** (0.019)
Italy	-6.460** (2.043)	0.086*** (0.023)
Ireland	1.887 (3.479)	-0.004 (0.031)
Germany	-4.314 (3.968)	-0.042 (0.028)
Observations	875	971

Note. AME = Average Marginal Effect; SE = Standard Error; EQ-5D-5L = Five-level EuroQol-5 Dimension; EQ-VAS = EuroQol Visual Analogue Scale; Disutility = 1 – EuroQol-5 Utility; ref = Reference category; CR = Care Recipient. A Generalised Linear Model (GLM) with a quasi-Poisson family was used for the EQ-5D VAS score. Disutility was modelled using a two-part model with a logit model in the first part and a GLM with a log link and gamma distribution in the second part. *p < .05; **p < .01; ***p < .001.

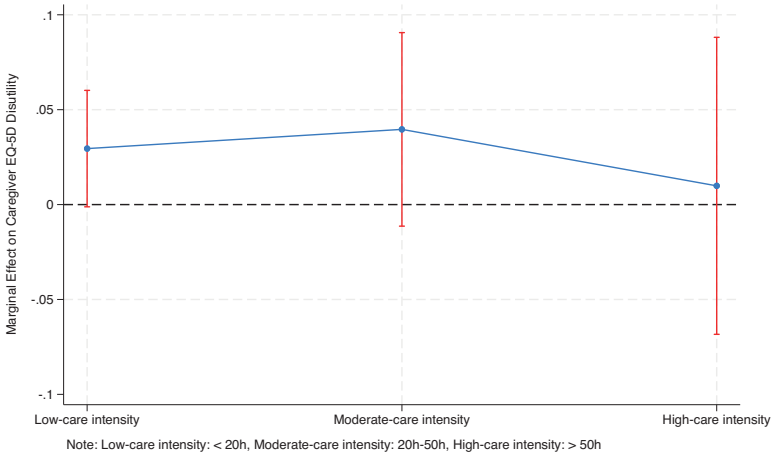


Figure 3.7. *Average Marginal Effects of Being a Primary Caregiver on Caregiver EQ-5D Disutility by Care Intensity (With 95% CI)*

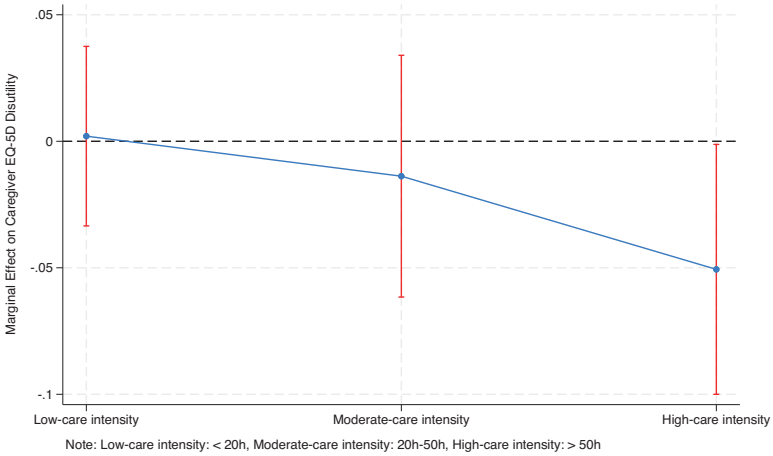


Figure 3.8. *Average Marginal Effects of Receiving Respite Care on Caregiver EQ-5D Disutility by Care Intensity (With 95% CI)*

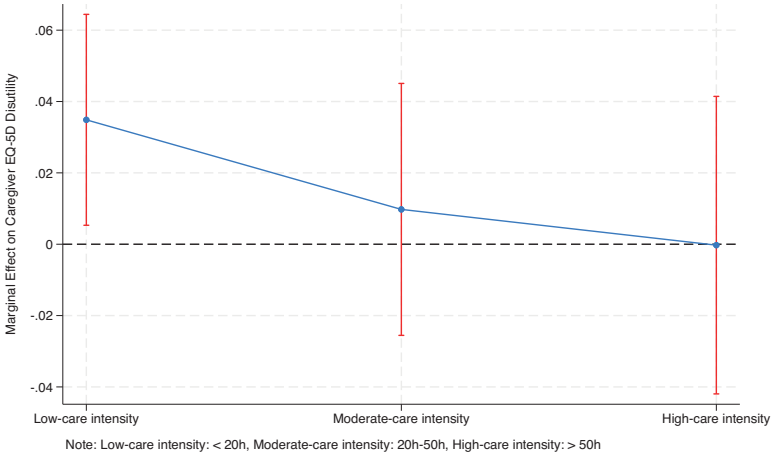


Figure 3.9. *Average Marginal Effects of Receiving In-Kind Services on Caregiver EQ-5D Disutility by Care Intensity (With 95% CI)*

Table 3.4 also presents the AMEs for EQ-VAS score derived from the quasi-Poisson regression. In line with the disutility analysis, being diagnosed with at least one health condition was associated with lower EQ-VAS scores. Caregiving intensity was negatively associated with

VAS scores, while perceived caregiving ability exhibited a positive association. Employment, meanwhile, was linked to higher scores, though this association was only observed among full-time caregivers. The duration of caregiving was not significantly associated with VAS scores. While primary caregiving showed no significant relationship with VAS scores, co-residence, by contrast, was significantly associated with lower scores. However, the interaction between co-residency and caregiving intensity suggested that this negative association was significant only for the moderate-care intensity group (see Figure 3.10). Caregivers with children residing in their households experienced lower VAS scores, and those aged between 45 and 54 exhibited the lowest scores among all age groups. Receiving financial support and in-kind services was not significantly associated with VAS scores. Meanwhile, respite care showed a statistically significant positive association only for caregivers in the high-intensity group (see Figure 3.11). Cross-country variations in VAS scores were observed, with Polish, Swedish and Italian caregivers exhibiting lower scores than Dutch caregivers.

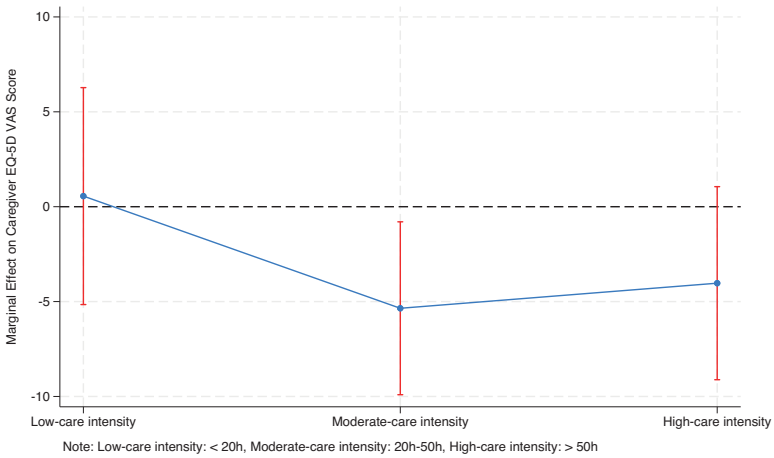


Figure 3.10. *Average Marginal Effects of Co-Residence on Caregiver EQ-VAS Score by Care Intensity (With 95% CI)*

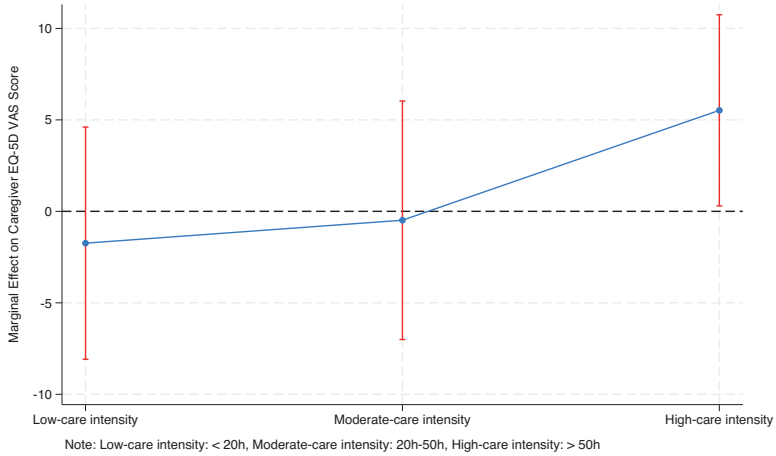


Figure 3.11. *Average Marginal Effects of Receiving Respite Care on Caregiver EQ-VAS Score by Care Intensity (With 95% CI)*

3.3.3. Labour Market Effects

Table 3.5 presents a summary of the labour market effects variables. More than one-third of employed caregivers (39%) reported reducing their working hours due to caregiving responsibilities. With respect to self-reported at-work productivity, the average productivity loss amounted to 32.26%, signifying that caregivers, on average, operated at 67.74% of their typical work productivity. Nearly one-third of caregivers (32%) maintained their customary productivity levels, whereas 6.9% reported a total inability to work (see Figure 3.12).

Table 3.5. *Summary of Labour Market Effects Variables*

	N	
Reduced working hours, n (%)	394	
No		241 (61%)
Yes		153 (39%)
Productivity loss at work, Mean (SD)	393	32.26 (32.89)

Note. German data were excluded due to the small sample size (n = 13).

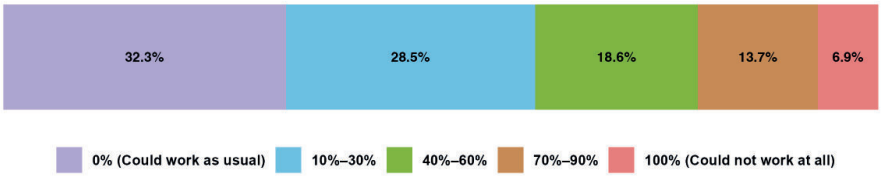


Figure 3.12. *Productivity Loss at Work as a Result of Caregiving*

Table 3.6 reports the AMEs from the logistic regression model examining the determinants of work reduction. The results indicated a significant disparity between male and female caregivers, with male caregivers being 17 percentage points less likely to report reducing their work hours. Compared to part-time employment, full-time employment was associated with a 27-percentage-point lower probability of work reduction. Conversely, co-residency was associated with a 10-percentage-point increase in the probability of work reduction. Additionally, providing over 20 hours of care per week and caring for an individual dependent on all ADLs were associated with a 14- and 16-percentage-point higher probability of work reduction, respectively. No significant cross-country differences were detected. Concerning self-reported at-work productivity, both caregiving intensity and co-residency were significantly associated with productivity declines. Notably, productivity reductions, significant at the 10% level, were observed among Italian caregivers and those diagnosed with one or more health conditions (see Table 3.7).

Table 3.6. *Average Marginal Effects from the Logistic Regression Model on Determinants of Work Reduction*

	Reduction of Working Hours
	AME (SE)
Age (ref: 18–44)	
45–54	0.100 (0.065)
55–64	0.022 (0.065)
Gender (ref: Female)	
Male	-0.174* (0.088)
Employment status (ref: part-time)	
Full time	-0.271*** (0.050)
Diagnosed with a health condition (ref: No)	
Yes	0.059 (0.048)
Primary caregiver (ref: No)	
Yes	0.003 (0.068)
Co-resident caregiver (ref: No)	
Yes	0.096*(0.053)
Hours of care per week (ref: < 20)	
≥ 20	0.144* (0.060)
Total months of caregiving	0.000 (0.000)
CR's dependency level (ref: Independent or partially dependent)	
Dependent	0.156** (0.051)
Financial support (ref: No)	
Yes	0.000 (0.070)
Respite care (ref: No)	
Yes	0.187 (0.121)
In-kind services (ref: No)	
Yes	0.053 (0.087)
Country of residence (ref: Netherlands)	
UK	-0.052 (0.069)
Sweden	0.100 (0.089)
Poland	-0.010 (0.088)
Italy	0.101 (0.073)
Ireland	0.030 (0.112)
Greece	0.086 (0.088)
Observations	376

Note. AME = Average Marginal Effect; SE = Standard Error; ref = Reference category; CR = Care Recipient. Standard errors are in parentheses. German data were excluded due to the small sample size (n = 13). *p < .05; **p < .01; ***p < .001.

Table 3.7. *Determinants of Productivity at Work*

	Beta (SE)
Age (ref: 18–44)	
45–54	3.090 (4.671)
55–64	-0.224 (4.722)
Gender (ref: Female)	
Male	-6.033 (5.256)
Employment status (ref: part-time)	
Full time	-3.485 (3.512)
Diagnosed with a health condition (ref: No)	
Yes	5.667 (3.522)
Primary caregiver (ref: No)	
Yes	-3.603 (4.892)
Co-resident caregiver (ref: No)	
Yes	9.057* (3.894)
Hours of care per week (ref: < 20)	
≥ 20	7.826* (3.909)
Total months of caregiving	-0.014 (0.023)
CR's dependency level (ref = Independent or partially dependent)	
Dependent	5.699 (3.795)
Financial support (ref: No)	
Yes	5.590 (6.643)
Respite care (ref: No)	
Yes	5.692 (5.212)
In-kind services (ref: No)	
Yes	-2.756 (6.152)
Country of residence (ref: Netherlands)	
UK	1.027 (5.327)
Sweden	-4.112 (5.391)
Poland	-3.783 (6.679)
Italy	9.937 (5.117)
Ireland	-0.469 (11.466)
Greece	4.061 (6.143)
Observations	369

Note. SE = Standard Error; ref = Reference category; CR = Care Recipient. Standard errors are in parentheses. German data were excluded due to the small sample size (n = 13). *p < .05; **p < .01; ***p < .001.

3.4. Discussion and Concluding Remarks

Amidst ongoing demographic shifts, the number of individuals requiring care is projected to rise sharply (Geerts et al., 2012). At the same time, policy reforms constraining access to formal care have reinforced the role of informal care as an indispensable pillar of LTC across Europe (Ranci & Pavolini, 2013). These trends underscore the pressing need for research

that explores the lived experiences of caregivers and the multifaceted challenges they confront. Developing effective policy responses that address these experiences and challenges is crucial for creating support mechanisms that sustain caregivers' engagement. A key step in this direction is to deepen our understanding of how caregiving affects caregivers' health and professional lives, as well as the factors shaping these outcomes. This chapter contributes to the literature by examining these effects through the lens of various individual and caregiving-related factors alongside cross-country variations.

The present study examines the relationship between informal caregiving and caregivers' HRQoL. Informal caregiving is found to be significantly associated with adverse health outcomes, as demonstrated by both EQ-5D utilities and EQ-VAS scores. Compared to general population norms, caregivers exhibit significantly lower scores on both measures across all surveyed countries. The magnitude of these disparities varies, with mean differences in VAS scores ranging from 6.41 to 17.60 and in EQ-5D utilities from 0.063 to 0.223. The latter can be interpreted to mean that caregivers experience between 23.0 and 81.4 fewer days of full health per year compared to the general population (Thomas et al., 2015). Furthermore, our estimates of caregiver disutility are consistent with the literature-reported range of 0.02 to 0.27 (E. Wittenberg et al., 2019). Notably, these estimates are comparable to those observed in chronic conditions such as deafness and bronchopulmonary dysplasia and may even exceed those associated with conditions like hematologic disorders and psoriasis (Van Wilder et al., 2019).

A closer examination of HRQoL relative to caregiving intensities across countries provides significant insights. Caregivers offering low-intensity care in Germany, Ireland, Poland, and the UK exhibit no significant differences from the general population. While these findings lend no support to the 'caring confers health benefit' hypothesis—even in situations of low-intensity caregiving—the evidence from Italy and the Netherlands directly contradicts

it. In these countries, significant declines in HRQoL are observed among low-intensity caregivers, challenging the positive effects suggested by the hypothesis (Thomas et al., 2015).

In Italy, reduced HRQoL may be tied to the inherent reliance on informal, family-based care with scant public support, placing a significant burden on caregivers, even at lower care intensities (Wulff et al., 2020). Conversely, the situation in the Netherlands presents a more complex picture. Although the country is recognised for having one of Europe's most generous LTC systems (OECD, 2021), Dutch caregivers providing low-intensity care report reduced HRQoL akin to their Italian counterparts. This outcome may be linked to recent reforms of the LTC system that progressively reduced the availability of institutional care, shifting a greater responsibility onto caregivers (Maarse & Jeurissen, 2016). In this transition, many caregivers might find themselves unprepared and overwhelmed by even low-intensity caregiving tasks, which they previously expected to be managed within institutional settings (Broek et al., 2015).

The findings concerning caregivers providing high-intensity care paint a distressingly clear picture of vulnerability and disadvantage. These caregivers exhibit substantially lower HRQoL than the general population, with VAS score decreasing by 9 to 21 points and utility dropping between 0.09 and 0.25. These utility losses equate to up to more than three months of lost days of full health. This pervasive decline, observed across various LTC systems ranging from limited to more supportive, highlights a widespread shortfall in effectively addressing the needs of this group. The results leave little room for identifying and promoting effective best practices. Instead, they contribute to a growing body of evidence that high-intensity caregivers urgently require focused, targeted policy interventions (Cormican et al., 2022; Y. Zhang & Bennett, 2024).

The negative association between caregiving intensity and caregivers' HRQoL is also reflected in our regression analyses, with moderate and high-intensity care being linked to

significantly lower HRQoL. This finding aligns with mounting evidence that caregiving intensity is a determinant of caregiver quality of life (Chappell et al., 2023; Cook et al., 2018). Additionally, the care recipient's dependency status in ADLs emerges as another significant factor, which aligns with the theoretical and empirical views that such dependency increases the demands and burden placed on caregivers (Andersen & Newman, 1973; Broese van Groenou & De Boer, 2016; Lindt et al., 2020).

In contrast, caregiving duration does not appear to be associated with caregiver HRQoL. This finding may point towards the 'adaptation hypothesis' rather than the 'wear-and-tear' hypothesis. Nonetheless, substantiating these wear-and-tear and adaptation processes requires longitudinal studies that examine both short- and long-term temporal changes in caregiver HRQoL.

Our findings also suggest that age and household composition are significantly associated with caregiver HRQoL. Caregivers aged 45–54 have significantly lower HRQoL, primarily reflected in EQ-VAS scores. Similarly, caregivers with one or more children at home are associated with lower HRQoL. These groups likely represent 'sandwich caregivers' or 'double-duty caregivers', managing care for both their ageing parents and their own children (Brenna, 2021). This dual responsibility may impose additional physical, psychological, financial, and time pressures, potentially contributing to declines in HRQoL (Pashazade et al., 2024).

Employment status is significantly associated with caregiver HRQoL, with both full-time and part-time employment linked to better outcomes, though the association for part-time employment is only evident in EQ-5D utility. This relationship has been documented in the literature and can be understood through economic and psychological mechanisms (Doebler et al., 2017; Provencher et al., 2003). Economically, employment provides financial stability and

future prospects, which may buffer against stress related to economic uncertainty (Krisor & Rowold, 2014; Nightingale et al., 2022; O'Neill et al., 2021). Psychologically, employment offers structured time away from caregiving, allowing caregivers to mentally disengage from their duties while benefiting from social interactions in the workplace (Krisor & Rowold, 2014; O'Neill et al., 2021). This balance between work and caregiving responsibilities can give caregivers greater control, promote self-fulfilment, and ultimately enhance HRQoL (Doebler et al., 2017). While these mechanisms provide a rationale for why employment might be linked to better HRQoL, the direction of this observed association cannot be determined given the cross-sectional nature of the analysis. It cannot be ruled out that caregivers who experience fewer HRQoL declines are more likely to maintain employment, rather than employment itself mitigating declines in HRQoL. Further longitudinal research is needed to better understand the direction of this relationship.

Our analysis reveals that primary caregiving is associated with poorer HRQoL. This finding aligns with existing literature linking primary caregiving to adverse health and well-being outcomes (Gonçalves-Pereira et al., 2020; Marino et al., 2020). However, a notable pattern emerges when examining the interaction between primary caregiving and care intensity. Care intensity seems to exert a crowding-out effect on the impact of primary caregiving, with marginal evidence of this impact only in low-intensity care situations. This finding suggests diminishing marginal effects of primary caregiving as care intensity increases. At low levels of care, the responsibilities inherent to the primary caregiver's role, such as coordinating services and making care decisions, seem to disproportionately augment the burden, leading to a decrease in HRQoL (Marcum et al., 2020). Conversely, as caregiving intensity escalates, the marginal effect of being the primary caregiver on HRQoL appears to diminish, possibly because both primary and non-primary caregivers confront such high care demands that distinctions between their roles become less significant.

Our findings also support the established correlation between co-residence and poorer caregiver health, attributed to the obligatory nature of the care (Y. Zhang & Bennett, 2024), blurred boundaries between personal time and care duties (Stoller & Pugliesi, 1989), loss of routine, and fewer opportunities for networking or recovery (Bamford et al., 1998), alongside heightened distress (Hirst, 2003). Furthermore, the interaction between care intensity and co-residence indicates a negative association with HRQoL exclusively at moderate care intensity. At low levels of care, caregivers seem to have sufficient capacity to cope with the additional burdens associated with co-residency without significant influence on their HRQoL. Conversely, caregivers providing intense care operate at nearly maximum capacity, and co-residence does not seem to further deteriorate their HRQoL, likely because the overwhelming demands dominate their experience regardless of living arrangements. However, at moderate care intensity, caregivers seem to be at a 'tipping point' where the added responsibilities and stress due to co-residency can push them beyond their manageable capacity. The accumulation of unplanned tasks and the disruption of boundaries between caregiving and personal life can upset the delicate balance that caregivers at this level attempt to maintain, leading to a significant decline in their HRQoL.

Turning to the receipt of support services, the study reveals no significant correlation between financial support and HRQoL among caregivers. Conversely, a positive association is evident between respite care and HRQoL for those providing high-intensity care. This observed benefit for high-intensity caregivers may reflect increasing marginal effects of respite care as care intensity rises. Intensive caregivers often face overwhelming demands; here, respite care seems to provide a significant reprieve, potentially leading to meaningful improvements in their HRQoL. For caregivers providing low or moderate levels of care, however, the marginal benefits of respite care appear limited. While the caregiving demands these caregivers face may

still be burdensome, these demands do not appear to amount to a situation that could meaningfully benefit from respite interventions.

The analysis of additional in-kind support services, such as training, counselling, and information, presents a contrasting scenario. These services show no association with improved HRQoL for moderate or high-intensity caregivers, with even a negative association observed among the low-intensity group. This finding signals an unexploited potential, as caregivers' perceived ability to manage caregiving tasks—which these services are intended to enhance—is significantly positively associated with HRQoL. To explore the negative association between these in-kind support services and HRQoL among the low-intensity care group, we analysed their EQ-5D responses through binary logistic regression. The results indicate that low-intensity caregivers receiving these services are 12% and 13% more likely to report problems in the 'anxiety/depression' and 'usual activities' dimensions, respectively, compared to those not receiving these services. These associations may reflect a mismatch between the services provided and the actual needs of the caregiving situation. The receipt of these services might inadvertently elevate perceived caregiving demands beyond actual requirements, leading to increased anxiety and an undue sense of obligation to exceed necessary caregiving duties. Furthermore, attending these services may disrupt these caregivers' usual activities, such as work, study, housework, family responsibilities, or leisure activities.

Our results concerning cross-countries differences in HRQoL appear to provide some middle ground between the two prevailing hypotheses in the literature. Specifically, caregivers in Italy exhibit particularly low HRQoL, consistent with the North-South gradient in caregiver health outcomes (Brenna & Di Novi, 2016; Uccheddu et al., 2019). Conversely, despite documented variations in LTC systems, no significant differences are found between the Netherlands, the reference country, and Germany, Ireland, or the UK. This absence of disparities supports the notion that once detailed information about caregiving situations is

considered, commonalities across countries with varying LTC systems become apparent (Bom & Stöckel, 2021; Kaschowitz & Brandt, 2017). Poland and Sweden demonstrate a distinct pattern, with EQ-5D utility and VAS scores reflecting opposing trends compared to the Netherlands: higher EQ-5D utility (indicated by lower EQ-5D disutility) contrasted with lower EQ VAS scores. This divergence suggests that the HRQoL impairments experienced by caregivers in these countries may be more influenced by dimensions of health not captured by the EQ-5D, such as psycho-social aspects (Chen & Olsen, 2020; Devlin & Brooks, 2017). This pattern highlights the complementarity of these measures in capturing the multifaceted nature of caregiver HRQoL.

The second part of this analysis examines the labour market effects of informal care provision. The findings reveal a significant association between informal caregiving and work hours, consistent with previous studies suggesting that caregivers are more likely to work fewer hours (Kotsadam, 2011). In line with existing literature (Carmichael & Charles, 2003), our findings show a gender-specific association with work time, with female caregivers disproportionately more likely than males to reduce paid work in favour of informal caregiving. In addition to gender, our results indicate a correlation between the caregiving situation and caregivers' work hours. Co-resident caregivers and those providing intense care are markedly more likely to reduce their work schedules. This pattern, where high caregiving responsibility is linked to reduced work hours, is well-supported in the literature (Carmichael et al., 2008; Sugawara & Nakamura, 2014).

While the impact of caregiving on work hours has been widely investigated, the impact on at-work productivity remains understudied, possibly due to measurement challenges. Our analysis suggests an association between care intensity and work productivity, with caregivers providing intensive care reporting significantly greater losses. Although the literature suggests that caregivers need and value receiving support services (Savard et al., 2006), our findings

indicate that these services are not associated with better work-related outcomes. This finding further points to a potential mismatch between the support provided and caregivers' needs.

There were some limitations in this study. The study sample, while diverse, was not representative of the caregiving population in the studied countries. This lack of representativeness in our sample could compromise the estimation of population parameters, particularly the mean differences in EQ-VAS scores and EQ-5D utilities between caregivers and the general population. For example, females, primary caregivers, and those with high levels of education were overrepresented in our sample. The overrepresentation of female caregivers likely did not significantly affect our estimated mean differences, as gender was accounted for when comparing our sample's HRQoL and population norms. Additionally, this overrepresentation of females is consistently observed in studies on informal care (Denham et al., 2020; Oldenkamp, Hagedoorn, Stolk, et al., 2017) and reflects their actual dominance in informal care provision (Zigante, 2018).

The overrepresentation of primary caregivers and highly educated caregivers in our sample likely had opposing effects. On the one hand, the predominance of primary caregivers might have inflated the estimated mean differences in HRQoL between caregivers and the general population. On the other hand, higher educational attainment —consistently associated with better HRQoL in population norm studies—might have deflated these differences. Although the exact impact of these overrepresentations on our results cannot be quantified, we believe that our estimates for the mean differences in HRQoL provide a reliable approximation, especially when primary caregivers are of concern.

Moreover, it is important to acknowledge that the population norms employed in this study were derived from a general public sample, which likely included individuals engaged in informal caregiving and experiencing care-related challenges. This raises the possibility that

our findings may underestimate the true extent of HRQoL declines. Several methodological improvements are warranted to enhance the precision of future assessments. First, population norms should incorporate caregiving activities as a key variable, much like they currently account for demographic factors such as age, gender, and, in some cases, education. Second, future studies should employ representative samples and well-matched comparison groups of non-caregivers, ideally within a longitudinal design, to estimate the causal effect of caregiving on HRQoL. A robust counterfactual group would consist of individuals with similar characteristics who were at risk of becoming caregivers but did not assume the role. This approach would strengthen causal inference by helping to disentangle the specific impact of caregiving from confounding factors.

Another limitation of this study relates to our instrument of choice, the EQ-5D, for measuring caregiver HRQoL. This choice was largely driven by pragmatic considerations. The EQ-5D is widely accessible in numerous languages, with country-specific value sets and population norms available for many countries, making it particularly well-suited for cross-country research. Additionally, its generic nature permits comparisons across diverse populations and interventions (Devlin & Brooks, 2017). However, this same characteristic also raises concerns regarding its capacity to fully capture the complex health impacts of caregiving (Reed et al., 2017). While we acknowledge these concerns, we maintain that using the EQ-5D contributes significantly to the comparability, interpretability, and overall value of our findings.

The Care-related Quality of Life (CareQol) and the ICEpop CAPability Measure for Older People (ICECAP-O) present promising alternatives to the EQ-5D. The CareQol is specifically designed to measure caregivers' quality of life, addressing aspects that the EQ-5D may overlook, such as relational and financial problems (Brouwer et al., 2006). Similarly, the ICECAP-O broadens the scope of assessment to include overall well-being and capabilities, offering a potentially more comprehensive understanding of caregivers' lives (Grewal et al.,

2006). Nonetheless, both measures face challenges, including issues of validity, limited language availability, limited availability of country-specific value sets, and restricted integration into policymaking frameworks (Dow et al., 2018; Voormolen et al., 2021). A pragmatic approach for future research could involve using multiple measures concurrently. Such an approach could draw on the strengths of each instrument while addressing their individual limitations, thereby providing a richer and more nuanced depiction of caregivers' HRQoL.

A further limitation pertains to the timing of data collection, which transpired during the COVID-19 pandemic. It is possible that participants experienced significant changes in their caregiving roles due to the implementation of COVID-related restrictions. Numerous studies have demonstrated that the COVID-19 pandemic has intensified caregivers' burdens and strains, adversely affecting their health and financial outcomes (Beach et al., 2021; Bergmann & Wagner, 2021). To evaluate the potential influence of COVID-19 on caregivers' HRQoL, we analysed temporal changes within each country. Specifically, for each country, we compared the mean VAS score and mean EQ-5D utility across multiple time points throughout the data collection period using Analysis of Variance (ANOVA) and the Kruskal-Wallis test. No significant differences were observed, indicating that caregivers' HRQoL remained stable despite the evolving COVID-19 situation and corresponding countermeasures.

Finally, an inherent limitation of this study lies in its reliance on cross-sectional data, which provides only a snapshot of the caregiving experience at a single point in time. This design constrains the ability to infer causal relationships or capture temporal dynamics. Longitudinal studies, by contrast, would allow for the investigation of causal effects and temporal trajectories while also offering insights into the elasticity of HRQoL with respect to caregiving intensity, the type of care provided, and responses to specific circumstances, such as caregiving in terminal illness and bereavement. Moreover, as future studies investigate the

effectiveness of support services, adopting rigorous designs—ideally randomised controlled trials— will be essential. Such studies should incorporate adequate sample sizes, comprehensive dyadic data collection, and cost information to enable a thorough economic evaluation (Gori et al., 2016).

Chapter 4

The Economic Costs of Informal Care: Estimates from a National Cross-Sectional Survey in The Netherlands

4. The Economic Costs of Informal Care: Estimates from a National Cross-Sectional Survey in The Netherlands‡

Abstract: Faced with an unprecedented demand for long-term care, European health care systems are moving towards mixed care models, where the welfare state and informal caregivers share care responsibilities. While informal care is often viewed as a means of alleviating pressure on public care, it comes with significant economic costs for caregivers, their employers, and society at large. This study uses nationally representative data to estimate the total direct (informal care time and out-of-pocket costs) and indirect (productivity) economic costs of informal care in the Netherlands in 2019. Informal care time costs are estimated using the opportunity cost and the proxy good methods. Indirect costs are estimated using the human capital and friction cost approaches. Our results reveal the considerable annual societal cost of informal care in the Netherlands, ranging between €17.5 billion and €30.1 billion, depending on the valuation approach. These costs are equivalent to 2.15% and 3.71% of Dutch GDP in 2019, comparable to the public expenditure on long-term care in that year. Female caregivers account for slightly more than half (53%–57%) of the total costs. Around 57%–88% of these costs are in the form of informal care time. The main driver of indirect costs is the temporary cessation of work, which comprises 12%–17% of the total costs. Findings corroborate that substantial resources, yet thus far largely disregarded, are spent on informal care even in a country with a relatively generous public long-term care system.

‡ This chapter is based on Elayan, Angelini, et al. (2024), published in the *European Journal of Health Economics*. Data were retrieved from the Netherlands Institute for Social Research. The study was conducted during a secondment at the Netherlands Institute for Social Research.

4.1. Introduction

Since the 1960s, the demographic landscape of Europe has undergone significant changes. The most notable transformation has perhaps been the ageing of the population, driven by the combined effects of declining fertility rates and increasing life expectancy (Statistics Netherlands, 2021; World Bank, 2022a). This trend is reflected in the old-age dependency ratio, which has more than doubled from 16.1% in 1960 to 33.5% in 2020 (OECD, 2023b). Currently, nearly one-fifth of the European Union population is 65 or older, a proportion projected to rise to 30.9% by 2050, with the fastest growth anticipated in the 80 + age category (World Bank, 2022d). While population ageing is in many ways a success story, it poses significant challenges to the sustainability of public services such as pensions, health care, and long-term care (LTC).

In response to the escalating demand for LTC, European countries have enacted diverse policy reforms. Despite this diversity, a prevalent trend is discernible: a contraction in eligibility for and the scale of institutional care, accompanied by a growing reliance on informal care (Verbakel, 2018a). This policy shift is primarily predicated on the premise that informal care can serve as a cost-saving strategy, efficiently addressing the growing demand for LTC while simultaneously curbing the associated costs (Jongen et al., 2016). One critique of this cost-saving notion is that it overlooks the already substantial amount of informal care being provided, thus overestimating the potential for 'untapped' informal care (Maarse & Jeurissen, 2016). This critique finds empirical corroboration from the 2016 European data, which indicates that nearly 13% of the population, over 76 million people, actively engaged in informal caregiving, collectively amassing an astounding 72 billion hours of care (Peña-Longobardo & Oliva-Moreno, 2022). Concerns also persist regarding the future availability of informal care. Ribeiro et al. (2022) project that the caregiver support ratio, defined as the number of individuals aged 45–64 available to provide care for each older adult aged 80 +, will steadily decrease throughout Europe in the coming decades. Specifically, by 2050, this ratio is

estimated to drop to just two potential informal caregivers for each older adult, significantly down from the approximately five-to-one ratio observed in 2020.

This notion of cost savings is also criticised for disregarding the negative externalities of informal care, including the expenses incurred by informal caregivers, their employers, and society as a whole (Maarse & Jeurissen, 2016). Fast et al. (1999) denote these costs as the 'hidden costs' of informal care and formulate a taxonomy that divides them into two primary categories: economic and non-economic costs. The latter, termed intangible costs, arise from potential declines in the physical, social, and emotional well-being of informal caregivers. Furthermore, the taxonomy identifies three main sources of economic costs associated with informal care, including employment-related costs, such as foregone employment opportunities or diminished productivity; out-of-pocket expenses that caregivers would not incur without providing care; and caregiving labour, which encompasses the time devoted by informal caregivers to providing care. In the field of health economics, employment-related costs are conventionally classified as indirect (productivity) costs, while caregiving labour and out-of-pocket costs are commonly classified as direct costs (Razzouk, 2017).

The inclusion of informal care costs in health economic evaluations and cost-of-illness studies has recently gained traction, but it remains an uncommon practice (Oliva-Moreno et al., 2017). Several scholars caution against the negative consequences of omitting these costs when evaluating policies and making resource allocation decisions. For instance, a systematic review of economic evaluations in areas where informal care is significant, conducted by Krol et al. (2015), demonstrates the significant impact that including informal care costs can have on the outcomes of these evaluations. This impact is likely to be even more pronounced in economic evaluations of support services and technologies for caregivers, such as training programmes and caregiver robots (Weatherly et al., 2014). These concerns are echoed by B. van den Berg et al. (2004), who argue that ignoring costs related to informal care in policy- and decision-

making can result in an 'invisible' shift of costs from the LTC sector to the informal economy without ever realising real cost savings for society.

This paper contends that the assertion of cost containment or savings concerning the ongoing policy shift towards informal care cannot be substantiated without carefully considering the costs associated with informal care. We examine the Netherlands, a country transitioning from an LTC system with a traditionally high residential care rate to an ageing-in-place model that increasingly depends on informal caregivers. This study aims to estimate the total societal economic costs of informal care in the Netherlands for 2019. These estimates will unveil the societal value of the significant yet often overlooked informal care resource—a value consistently omitted from national income accounts and mainstream economic discourse. This information can provide policymakers with a nuanced understanding of the multifaceted impacts of LTC policies across the entire care sector. Furthermore, this study offers essential insights into the dynamics between informal care and the labour market. These insights can inform the development of mechanisms that help caregivers balance paid employment with caregiving duties. Lastly, as global reliance on informal care grows, our findings promise to contribute to discussions in other countries grappling with the challenge of meeting the burgeoning demand for LTC.

4.2. Review of the Current Evidence on the Costs of Informal Care

Our literature review identified several studies estimating the national cost of informal care. In the United States, Chari et al. (2015) estimated the cost of informal care for older adults in 2012 to be in the range of US$221 billion to US$642 billion, corresponding to 1.36% to 3.95% of US GDP (Statista, 2023). The economic value of informal care in Australia in 2020 was estimated by Deloitte Access Economics (2020) to be between A$15.2 billion, using the

opportunity cost method, and A$77.9 billion, using the proxy good method, equating to 0.80% to 4.00% of Australia's GDP.

In Spain, Oliva-Moreno et al. (2019) determined that in 2013, adult informal caregivers provided an average of 96.6 h per week, with the annual cost per caregiver ranging from €27,140, using the opportunity cost method, to €83,056, using the proxy good method. However, the study's reliance on a small sample from two Spanish regions could limit its national representativeness. In Sweden, the cost of informal care in 2019 was estimated by Ekman et al. (2021) at 3.15%–4.01% of the country's GDP, notably including presenteeism and lost sleep due to informal care as cost components.

Ecorys Netherlands estimated the 2019 cost of informal care in the Netherlands to be between €22 billion, using the opportunity cost method, and €32 billion, using the proxy good method. The report, however, relied exclusively on data from published reports and articles, which lacked sufficient detail to capture the full scope of indirect (productivity) costs (Blanken et al., 2021). In Ireland, Hanly & Sheerin (2017) valued the informal care provided in 2011 at €5.3 billion (opportunity cost method), equivalent to 3.30% of the country's GDP, with female caregivers accounting for almost two-thirds of the total cost (Central Statistics Office Ireland, 2012). In a broader European context, Peña-Longobardo & Oliva-Moreno (2022) valued informal care in Europe in 2016 using data from the European Quality of Life Survey at approximately €576 billion, representing about 3.63% of Europe's GDP.

These findings underscore the significant economic impact of informal caregiving, an apparent trend across countries with diverse LTC systems. Moreover, we observe considerable methodological variations, resulting in conspicuous discrepancies in the outcomes. These disparities underscore the non-neutral role of the chosen valuation methods and the specific cost components considered. The present study enhances existing literature by leveraging

nationally representative individual-level data to precisely and comprehensively quantify the direct and indirect (productivity) costs of informal care. Acknowledging the impact of methodological choices, we employ the most commonly used methods for valuing informal care time and indirect (productivity) costs—namely, opportunity cost, proxy good, and contingent valuation methods for the former, and human capital and friction cost approaches for the latter. This strategy aligns our study with the predominant methodologies in caregiving research and significantly contributes to the field by providing relevant and comparable findings.

4.3. Methods

4.3.1. Data and Variables

The primary data source used in this study comes from the third wave of the Informal Care (IZG) Study, a nationally representative survey examining the provision of informal care among the noninstitutionalised population aged 16 years or older residing in the Netherlands. The study was conducted between September 10, 2019, and January 10, 2020, by Statistics Netherlands on behalf of the Netherlands Institute for Social Research. The survey was carried out among a random sample of 38,923 subjects drawn from the municipal personal records database that includes all residents of the Netherlands. A total of 12,348 participants completed the survey, with 71% of the responses collected through a web-based survey and the remaining 29% obtained through telephone interviews. Survey weights were developed by Statistics Netherlands to account for unequal probability of selection and non-response, thus allowing for estimates representative of the underlying target population. More details on the sampling methodology are available elsewhere (Schulte et al., 2020).

The survey commenced with demographic and household composition questions. Next, participants were presented with a definition of informal care (without specifying the term) and

were then asked if they had provided this type of support in the previous 12 months. The definition was: 'Providing help to friends or family with health problems. These can, for example, include your partner, family members, friends or neighbours who need help due to physical, psychological or mental limitations, or old age. Examples of such help include household activities, washing and dressing, companionship, transport and odd jobs. Help provided within the framework of your profession or volunteer work does not count in this regard' (de Klerk et al., 2021, p. 1782). This definition has three advantages. First, it is broad enough to encompass the full range of informal caregivers, including those who do not recognise themselves as such, without imposing minimum thresholds on the amount or duration of care provided. Second, it clearly distinguishes between informal care on one side and volunteer and professional care on the other. Third, it excludes care provided to healthy individuals (e.g., childcare). Participants identified as informal caregivers were then directed to a series of survey sections, each addressing a distinct aspect of informal care. The survey questions used in the costing analysis are presented in Table 4.1.

Table 4.1. *List of Survey Questions Used to Estimate Informal Care Costs*

Cost Component Assessed	Survey Question	Answer Choices
A. Direct costs		
A.1 Informal care time	On average, how many hours per week do you spend assisting the person you provide help to? Please exclude any time spent on normal housework or the usual support that family/household members provide to each other.	Number in the range 1–168
A.2 Out-of-pocket costs	Did you incur any additional costs associated with providing assistance? For example, travel or telephone costs.	Yes/No
	Adding these costs together, how much did you spend in euros in the last month?	• Less than €50 • Between €50 and €100 • Between €100 and €200 • Between €200 and €300 • Greater than €300
B. Indirect costs (productivity loss)		
B.1 Cessation of work	Did you stop working to provide help?	Yes/No
	Have you stopped working in the past 12 months to provide help?	Yes/No
	Have you stopped working temporarily in the past 12 months to provide help?	Yes/No

Cost Component Assessed	Survey Question	Answer Choices
B2. Reduction of work hours	Have you reduced your working hours in the past 12 months to provide help?	Yes/No
B3. Presenteeism (lost productivity while at work)	Did you work with less concentration due to the help you provided?	• No, not at all • Yes, a bit • Yes, very much
	How often were you distracted at work by the person you provided help to or by things you had to arrange for them?	• Daily • Weekly • Monthly • Rarely or never

4.3.2. General Approach

The present study estimated the economic cost of informal care from a societal perspective, where all relevant costs were considered, irrespective of whom they fall upon. We identified two broad domains of societal economic costs associated with informal care: direct and indirect (productivity) costs (Fast et al., 1999; Keating et al., 2014). Direct costs included the cost of time devoted to informal care and the out-of-pocket expenses incurred by caregivers (Razzouk, 2017). Indirect (productivity) costs encompassed losses in work productivity due to care-related absenteeism and presenteeism (Mattingly et al., 2022).

Economic costs of informal care were estimated using a bottom-up and prevalence approach. The estimation proceeded in two steps. The first step involved measuring the quantities of resources used (i.e., informal care time and out-of-pocket expenses) and lost productivity (i.e., lost paid-work time). Data on resource use and lost productivity were obtained from the Informal Care Study (see Table 4.1). The second step involved valuing these resources and productivity losses by assigning unit costs. Costs were then estimated by multiplying the quantities of these resources and losses by their respective unit costs. Unit costs were derived or estimated from official sources, published literature, or the Dutch Manual for Costing Studies in Health Care (Hakkaart-van Roijen et al., 2015). A full list of unit costs and their sources is provided in Table 4.A.1 in Appendix 4.A. All prices and unit costs were adjusted to 2019 prices using the Consumer Price Index (CPI) (Statistics Netherlands, 2023a).

Finally, a base-case analysis was developed using the best-available information and by applying the most conservative assumptions when data were lacking. Discounting of costs was not required since the time horizon was limited to one year. Weighted data were used in all analyses to obtain population estimates. All analyses were performed using the R software version 4.2.2 (R Core Team, 2022).

4.3.3. Cost Calculations

4.3.3.1. Direct Costs

The weekly cost of informal care time was calculated for each caregiver as the product of the reported weekly hours of informal care and its unit cost. This estimate was then multiplied by the reported number of weeks of care provided in the past year to obtain the annual cost.

The unit cost of informal care time was determined by assigning a shadow price based on the opportunity cost and proxy good methods. In the opportunity cost method, informal care time was valued in terms of leisure time forgone. Thus, the unit cost was set equal to the value of one hour of leisure time. The value of leisure time can be determined as a proportion of the national average gross wage or via methods such as conjoint analysis, contingent valuation, and studies on the value of travel time savings. Given the lack of agreement on a standardised approach for valuing leisure time, and in line with the conservative approach applied in our base-case analysis, we selected the most conservative estimate available for the Netherlands. Consequently, we set the value of one leisure hour at the monetary equivalent of one hour of non-business travel time saving, as derived from the official monetary values of time published by the Dutch Ministry of Infrastructure and the Environment (Kouwenhoven et al., 2014). By contrast, in the proxy good method, informal care time was valued at the labour market price of a close substitute (B. van den Berg et al., 2006). Following recommendations from the Dutch

Costing Manual, the unit cost of informal care time was set equal to the standard hourly rate of household care ('huishoudelijke zorg' in Dutch) (Hakkaart-van Roijen et al., 2015).

Previous research has shown that caregivers may report implausible hours of caregiving. Specifically, caregivers of severely dependent individuals may indicate that they provide continuous care, 24 h per day and seven days per week, due to the need to be constantly available for their care recipients (Hoefman et al., 2013). However, this is obviously implausible, as caregivers must also allocate time to fulfil their basic needs, such as personal care and sleep (Huls et al., 2022). Therefore, we imposed a minimum of 6 h per day for leisure, resulting in a maximum of 126 h per week available for work and informal care, calculated as (24 h–6 h) × 7 days. In cases where the combined time spent on work and care exceeded 126 h per week, the surplus was subtracted from the reported informal care time. Results without this weekly time cap are presented as a sensitivity analysis to facilitate comparisons with other studies, as recommended by Oliva-Moreno et al. (2017).

Out-of-pocket costs were directly measured in monetary terms in the survey. The monthly out-of-pocket cost was assumed to be the midpoint of the reported monthly range, or €300 for those who reported expenses in the €300 or more category. This figure was multiplied by the number of months of care provided to generate annual out-of-pocket costs. Missing values were imputed with the minimum value of less than €50.

4.3.3.2. Indirect (Productivity) Costs

The study identified three distinct types of care-related absenteeism: Prolonged Time Off (PTO), Temporary Time Off (TTO), and Reduced Hours at Work (RHW). PTO refers to when caregivers discontinue their employment due to the exigencies of providing care. On the other hand, TTO pertains to temporary time off from work for the same reasons. RHW encompasses the reduction in working hours for caregivers who retained their employment.

Productivity loss can also come in the form of presenteeism, which refers to diminished on-the-job productivity due to care provision. Indirect (productivity) costs were estimated only for the sub-sample of caregivers aged 16–75 years who reported one or more of these types of productivity loss. The unit cost of productivity loss, i.e., the value of one hour of forgone paid work, was set at the gender-specific hourly labour costs obtained from the Dutch Costing Manual (Hakkaart-van Roijen et al., 2015; Kanters et al., 2017).

Two methods were used to estimate indirect (productivity) costs: the human capital approach and the friction cost approach. In the human capital approach, weekly PTO costs were estimated as the number of work hours per week multiplied by the unit cost of productivity loss. The weekly costs were then annualised by multiplying them by the number of work weeks per year in the Netherlands (assumed to be 46 weeks per year). Given that PTO costs are by definition applicable only to non-working caregivers, the number of work hours per week was imputed from the age- and gender-specific national average working hours in 2019, as obtained from Statistics Netherlands (Statistics Netherlands, 2022b). Annual TTO costs were estimated as the product of the reported work hours per week, the duration of time off work (in weeks), and the unit cost of productivity loss. Since the exact duration of time off work was not recorded, it was assumed to correspond with half the number of weeks of care provided in the year preceding the survey. This assumption mirrors the pattern observed in Dutch unemployment data, indicating that the median duration of unemployment spanned half of the working year in 2019 (OECD, 2023a). Weekly RHW costs were estimated as the product of the unit cost of productivity loss and the mean difference in working hours per week between non-caregivers and caregivers who reduced their working hours (see Table 4.2 and Table 4.3). Weekly RHW costs were annualised in the same fashion as PTO costs, with a minor adjustment for caregivers who had TTO costs. The number of work weeks per year for these caregivers was adjusted by deducting the time off work to avoid double counting.

The same calculation procedures were followed for the friction cost approach; however, productivity losses were confined to a friction period of 12 weeks, as per the guidance in the Dutch Costing Manual (Hakkaart-van Roijen et al., 2015). While the human capital approach can yield estimates of productivity losses that are many times larger than those from the friction cost approach (Pike & Grosse, 2018), our study is unlikely to exhibit such marked discrepancies. This prediction stems from the one-year horizon of our research, which limits the human capital approach to assessing potential productivity loss over this one-year timeframe. This constraint, as opposed to the approach's capability to span a more extended, multi-year caregiving period, is expected to narrow its divergence from the friction cost approach.

To determine the cost of presenteeism, we made certain assumptions to convert the level of reduced concentration resulting from caregiving into a percentage reflecting work impairment. The levels of reduced concentration were converted as follows: 'No, not at all' = 0%, 'Yes a bit' = 25%, and 'Yes, very much' = 50%. Moreover, the frequency of caregiving-related distractions at work was transformed into a percentage of working days affected by such distractions per week. Based on a standard working month of four weeks, each with five working days, the frequencies were converted as follows: 'Daily' = 100%, 'Weekly' = 20%, 'Monthly' = 5%, and 'Rarely or never' = 0%. Weekly presenteeism hours were calculated as the product of the percentage of work impairment, the percentage of working days with distraction, and the reported weekly number of hours worked. The resulting figure was then annualised and monetised using an analogous approach as for RHW. Participants with missing values for distraction or reduced concentration at work were assumed to have no presenteeism costs. Given the difficulty in applying the friction cost approach in the context of presenteeism, the associated cost was estimated solely using the human capital approach. As presenteeism was not measured using a standardised instrument, we opted to omit the

corresponding costs from the base-case analysis and present them as part of a sensitivity analysis.

4.3.3.3. Total Annual Societal Cost

The total annual societal cost of informal care was estimated in three successive steps, drawing on the guide for estimating informal care costs developed by Landfeldt et al. (2019). The first step involved calculating the annual direct and indirect (productivity) costs for each caregiver in the sample, as previously described. In the second step, indirect (productivity) costs were adjusted to reflect the net societal productivity loss when informal care time was valued using the proxy good method (Landfeldt et al., 2019).

The proxy good method takes a societal perspective in that it regards informal care as a form of work that, similar to market work, uses time and energy to generate services of economic value (Engel et al., 2021; Hirway, 2015). This view implies that shifting time from market activities to informal caregiving does not constitute a loss of productive time but rather a reallocation of labour time from one work activity to another (White-Means, 1992). Nonetheless, such reallocation can still yield net cost if the societal value of the resulting market production losses outweighs that of the production gains from the informal care provided (Landfeldt et al., 2019). Therefore, in this analysis, we deducted the cost of informal care time for each caregiver (as measured by the proxy good method) from their indirect (productivity) costs to arrive at their net indirect (productivity) cost.

The literature presents conflicting views on the need for such cost adjustment when employing the opportunity cost method. Some contend that this method inherently adopts the perspective of the informal caregiver, valuing their care time at the forgone value of their best alternative use of that time (Roquebert & Tenand, 2021). Therefore, in cases like our study, where leisure is deemed the best alternative, the assumption of a trade-off exclusively between

informal care and leisure activities ensues, obviating the need for adjustment (Engel et al., 2021; Landfeldt et al., 2019). This is because leisure activities, unlike market work, do not directly contribute to producing goods or services and, therefore, do not need to be factored into estimating indirect (productivity) costs (Kooreman & Wunderink, 1996). Other scholars suggest a cautious approach, proposing that informal care time be adjusted by deducting lost market work time. This adjustment is to avoid potential double counting of time that might be reallocated between these two activities (Michalowsky et al., 2016, 2018). Reflecting these divergent perspectives, we reported the results of the opportunity cost method without adjustment in our base-case analysis and included the adjusted results in a sensitivity analysis.

Finally, we calculated the total cost for each individual in the sample by summing their direct and indirect (productivity) costs. We then aggregated these figures using survey weights to arrive at a nationally representative estimate of the total cost of informal care in the Netherlands.

4.3.4. Sensitivity Analysis

The base-case analysis represents the most conservative estimation of informal care costs. Deterministic one-way sensitivity analyses were performed to gauge the sensitivity of the results to the assumptions applied and the values of key parameters. This included applying alternative unit costs for leisure time. In particular, we applied the willingness-to-pay and willingness-to-accept values for leisure time suggested by Verbooy et al. (2018) for the Netherlands. We also assessed the stability of our results with respect to the 126-h weekly cap applied to the time available for work and informal care by recalculating the costs without this cap.

Furthermore, we quantified the potential overestimation in our opportunity cost base-case estimates due to the potential overlap between productivity losses and informal care time.

The analysis recalculated the opportunity costs using an adjusted measure of informal care time. This adjustment involved deducting caregivers' lost paid-work time from their reported informal care time. Finally, we calculated the costs associated with presenteeism using the human capital approach, as described in the Indirect (productivity) costs section.

4.4. Results

4.4.1. Sociodemographic Characteristics and Cost Variables

Table 4.2 shows the weighted and unweighted distribution of the main sociodemographic characteristics of survey participants, stratified by caregiver status. The final study population comprised 12,348 individuals, representing a weighted population of 14,222,458 noninstitutionalised adults (≥ 16 years) living in the Netherlands in 2019. Of the total sample, 4,483 participants were identified as informal caregivers and included in the subsequent analysis. Our results revealed statistically significant differences between the caregiver and non-caregiver groups in all characteristics examined. Compared to non-caregivers, caregivers tended to be older, female, married, and highly educated. While labour force participation rates were similar between the two groups, working caregivers were more likely to work part-time and fewer hours than their non-caregiver counterparts. Using survey weights, we estimated that there were approximately 5.1 million adult informal caregivers in the Netherlands in 2019, with a prevalence rate of approximately 36% among the adult population. The distribution of the main characteristics of the caregiver sample by gender is presented in Table 4.B.1 in Appendix 4.B.

Table 4.2. *Weighted and Unweighted Descriptive Statistics*

	Unweighted Sample (N = 12,348)			Weighted Sample (N = 14,222,458)		
Characteristic	**Caregiver, N = 4,483**	**Non-caregiver, N = 7,865**	**p-value†**	**Caregiver, N = 5,074,358**	**Non-caregiver, N = 9,148,100**	**p-value‡**
Age in years, Mean (SD)	52.72 (17.06)	50.97 (20.40)	<0.001	49.65 (17.04)	47.48 (20.11)	<0.001
Gender, n (%)			<0.001			<0.001
Male	1,931 (43%)	3,974 (51%)		2,261,174 (45%)	4,767,833 (52%)	
Female	2,552 (57%)	3,891 (49%)		2,813,183 (55%)	4,380,268 (48%)	
Relationship status, n (%)			<0.001			<0.001
Married	2,775 (62%)	3,938 (50%)		2,789,782 (55%)	3,961,995 (43%)	
Divorced	368 (8%)	676 (9%)		499,268 (10%)	824,802 (9%)	
Widow	191 (4%)	590 (8%)		187,921 (4%)	620,002 (7%)	
Never been married	1,149 (26%)	2,661 (34%)		1,597,386 (31%)	3,741,302 (41%)	
Education, n (%)			<0.001			<0.001
Primary	573 (13%)	1,356 (17%)		613,827 (12%)	1,470,203 (16%)	
Secondary	2,071 (46%)	3,310 (42%)		2,387,569 (47%)	3,850,790 (42%)	
Tertiary	1,678 (37%)	2,713 (34%)		1,907,523 (38%)	3,345,681 (37%)	
None of these	161 (4%)	486 (6%)		165,438 (3%)	481,426 (5%)	
Employment status§, n (%)			<0.001			<0.001
Not employed	1,117 (27%)	1,956 (29%)		1,161,678 (24%)	2,016,908 (25%)	
Part-time	1,740 (42%)	2,487 (36%)		2,028,172 (42%)	3,073,685 (37%)	
Full-time	1,281 (31%)	2,394 (35%)		1,608,936 (34%)	3,131,751 (38%)	
Not in the labour force¶	345	1,028		275,571	925,757	
Hours of work per week††, Mean (SD)	29.61 (12.86)	30.73 (13.78)	<0.001	29.99 (12.97)	31.08 (13.57)	<0.001

†Wilcoxon rank sum test; Pearson's chi-squared test.
‡Wilcoxon rank-sum test for complex survey samples; chi-squared test with Rao & Scott's second-order correction.
§Employment status refers to the employment status of the respondent during the year prior to the survey. Working full-time is defined as working 36 or more hours per week, and working part-time is defined as working less than 36 hours per week.
¶Individuals aged 76 years or older were considered out of the labour force.
††The number of working hours of employed respondents (n = 3,021).

Table 4.3 presents a summary of the identified cost items. In terms of the intensity of informal care, the mean weekly hours of care provided was 7.37, and the mean number of weeks of care per year was 40.93. Based on these figures, we estimated that approximately 1.55 billion hours of informal care were provided in the Netherlands in 2019. Moreover, more than 40% of caregivers reported out-of-pocket expenses, with 9% incurring monthly costs greater than €100.

The impact of caregiving on employment was assessed only for the subsample of informal caregivers aged 16 to 75 years who combined work and care in the year preceding the survey. Only 7% of the non-employed respondents in this subsample reported that they had discontinued work due to caregiving duties. Of those employed at the time of the survey, approximately 6% left work temporarily to provide care. Among those who worked for pay in the year before the survey, 10% reported a decrease in their weekly working hours, with an average reduction of approximately two hours compared to non-caregivers. Additionally,

nearly one-quarter of those who worked for pay reported experiencing impaired concentration (23%) or distraction at work (23%) due to their caregiving responsibilities. A weighted summary of cost items stratified by gender is presented in Table 4.B.2 in Appendix 4.B.

Table 4.3. *Summary of Cost Items*

Cost Item	N	Unweighted Sample (N = 4,483)	Weighted Sample (N = 5,074,358)
Direct cost items			
Hours of care per week (uncapped)	4,483		
Mean (SD)		7.98 (17.06)	7.65 (16.42)
Median		3	3
Range		1–168	1–168
Hours of care per week (capped)	4,483		
Mean (SD)		7.68 (14.62)	7.37 (14.06)
Median		3	3
Range		1–126	1–126
Hours of care per week (capped), n (%)	4,483		
Less than 5 h		2,838 (63%)	3,277,688 (65%)
Between 5 and 15 h		1,179 (26%)	1,296,502 (26%)
More than 15 h		466 (10%)	500,168 (10%)
Duration of informal care (weeks per year)			
Mean (SD)	4,483	41.40 (17.44)	40.93 (17.68)
Median		52	52
Range		1–52	1–52
Monthly out-of-pocket costs, n (%)	3,951		
No out-of-pocket costs		2,294 (58%)	2,634,969 (59%)
Less than €50		810 (21%)	905,920 (20%)
€50–€100		503 (13%)	559,290 (12%)
€100–€200		190 (5%)	214,554 (5%)
€200–€300		70 (2%)	74,629 (2%)
Greater than €300		84 (2%)	87,987 (2%)
Missing		532	
Indirect (productivity) cost items			
Prolonged cessation of work, n (%)	1,240[†]		
No		1,161 (94%)	1,218,962 (93%)
Yes		79 (6%)	89,962 (7%)
Temporary cessation of work, n (%)	2,794[‡]		
No		2,633 (94%)	3,166,113 (94%)
Yes		161 (6%)	188,402 (6%)
Reduction of working hours, n (%)	2,917[§]		
No		2,627 (90%)	3,159,877 (90%)
Yes		290 (10%)	341,883 (10%)
Hours of work per week, Mean (SD)	2,917[§]		
Caregivers who reduced work hours		28.41 (12.43)	28.93 (12.48)
Caregivers who did not reduce work hours		30.02 (12.73)	30.44 (12.82)
Distracted at work due to caregiving, n (%)	2,917[§]		
Rarely or never		2,153 (76%)	2,609,977 (77%)
Monthly		250 (9%)	286,275 (8%)
Weekly		296 (10%)	353,595 (10%)
Daily		137 (5%)	157,372 (5%)
Missing		81	
Less concentrated at work due to caregiving, n (%)	2,917[§]		
No, not at all		2,195 (77%)	2,625,759 (77%)
Yes, a bit		581 (20%)	714,946 (21%)
Yes, very much		60 (2%)	69,662 (2%)
Missing		81	

Note. Percentages may not add up to 100% due to rounding. Indirect (productivity) cost items were assessed only among subjects aged 16 to 75 years who combined work and care in the year preceding the survey.
[†]This sample refers to subjects who were not employed at the time of the survey.
[‡]This sample refers to subjects who were employed at the time of the survey.
[§]This sample refers to subjects who had worked for pay during the year preceding the survey.

4.4.2. Base-Case analysis

4.4.2.1. Opportunity Cost Method

Table 4.4 presents the annual costs of informal care in 2019, as calculated using the opportunity cost method. The total cost of informal care time was estimated at €12.41 billion, corresponding to an average annual cost of €2,445 per informal caregiver. The out-of-pocket expenses incurred by informal caregivers amounted to €1.57 billion, averaging €309 per caregiver annually.

Table 4.4. *Total Annual Costs of Informal Care Based on the Opportunity Cost Method.*

		Human Capital Approach				Friction Cost Approach			
Domain	**Cost item**	**Costs (€)**	**Mean (€)**	**Share of total costs, %**	**Female-to-male cost ratio**	**Costs (€)**	**Mean (€)**	**Share of total costs, %**	**Female-to-male cost ratio**
A. Direct costs of informal care									
A.1	Informal care time	12,406,021,969	2,445	57%	1.36	12,406,021,969	2,445	71%	1.36
A.2	Out-of-pocket expenses	1,569,367,944	309	7%	1.10	1,569,367,944	309	9%	1.10
Sub-total		13,975,389,913	2,754	64%	1.33	13,975,389,913	2,754	80%	1.33
B. Indirect (productivity) costs									
B.1	Reduction of work hours	722,361,121	142	3%	1.43	275,211,711	54	2%	1.29
B.2	Temporary cessation of work	3,762,200,914	741	17%	0.83	2,145,917,683	423	12%	0.81
B.3	Prolonged cessation of work	3,416,342,780	673	16%	0.76	1,101,077,929	217	6%	0.76
Sub-total		7,900,904,815	1,556	36%	0.84	3,522,207,323	694	20%	0.83
Total societal costs		21,876,294,728	4,310		1.13	17,497,597,236	3,448		1.21

Note: Percentages may not add up to 100% due to rounding.

The friction cost approach estimated the total annual indirect (productivity) costs to be €3.52 billion, with an average annual cost of €694 per caregiver. Meanwhile, the human capital approach produced a higher estimate of indirect (productivity) costs (by a ratio of 2.24), totalling €7.90 billion, with an average annual cost of €1,556 per caregiver. The largest contributor to indirect (productivity) costs was the temporary cessation of work, which accounted for 12%–17% of the total cost.

The aggregate cost of informal care, including both direct and indirect (productivity) costs, was estimated to range from €17.50 billion to €21.88 billion, depending on the method used to estimate indirect (productivity) costs. The cost of informal care time was the most significant cost component, constituting 57%–71% of the total cost, followed by indirect (productivity) costs (20%–36%) and out-of-pocket costs (7%–9%).

The gender-specific analysis highlighted disparities in the economic impact of informal caregiving. The female-to-male cost ratios for informal care time and out-of-pocket expenses were 1.36 and 1.10, respectively, indicating a greater share of costs borne by female caregivers in both categories. Indirect (productivity) costs also carried gender distinctions. The ratio for reduced work hours stood at 1.29–1.43, pointing to higher costs incurred by female caregivers. In contrast, the ratios for temporary and prolonged work cessation were significantly below one, implying higher costs borne by male caregivers. These trends were consistent across both the human capital and friction cost approaches. A breakdown of results by gender is presented in Table 4.B.3 in Appendix 4.B.

4.4.2.2. Proxy Good Method

Using the proxy good method (see Table 4.5), we estimated the annual cost of informal care time at €23.42 billion, with an average annual cost of €4,615 per informal caregiver. The annual indirect (productivity) costs were estimated to range from €1.70 billion to €5.15 billion using the friction cost and human capital approaches, respectively. As expected, the proxy good method yielded considerably lower estimates for indirect (productivity) costs compared to the opportunity cost method. This outcome was due to the production gains from reallocating time from paid labour to informal care, which partially offset the indirect (productivity) costs.

Table 4.5. *Total Annual Costs of Informal Care Based on the Proxy Good Method*

Domain	Cost item	Human Capital Approach				Friction Cost Approach			
		Costs (€)	Mean (€)	Share of total costs, %	Female-to-male cost ratio	Costs (€)	Mean (€)	Share of total costs, %	Female-to-male cost ratio
A. Direct costs of informal care									
A.1	Informal care time	23,420,148,790	4,615	78%	1.36	23,420,148,790	4,615	88%	1.36
A.2	Out-of-pocket expenses	1,569,367,944	309	5%	1.10	1,569,367,944	309	6%	1.10
Sub-total		24,989,516,734	4,924	83%	1.34	24,989,516,734	4,924	94%	1.34
B. Indirect (productivity) costs									
Sub-total		5,145,262,608	1,014	17%	0.79	1,700,520,930	335	6%	0.79
Total societal costs		30,134,779,342	5,938		1.23	26,690,037,664	5,259		1.30

Note: Percentages may not add up to 100% due to rounding.

The total annual costs of informal care ranged between €26.69 billion and €30.13 billion (equivalent to €5,259–€5,938 per caregiver), depending on whether the friction cost or human capital approach was used to estimate the indirect (productivity) costs. Informal care time costs constituted 78%–88% of the total costs, while indirect (productivity) and out-of-pocket costs accounted for 6%–17% and 5%–6%, respectively.

The gender-specific analysis based on the proxy good method yielded results that echoed those of the opportunity cost method, with similar gender disparities observed across all cost categories. Detailed results by gender are shown in Table 4.B.4 in Appendix 4.B.

4.4.2.3. Sensitivity Analysis

The sensitivity analysis demonstrated that the unit cost of leisure time greatly impacted the cost estimates. Using the willingness-to-pay value for leisure time proposed by Verbooy et al. (2018) resulted in annual costs ranging from €21.08 billion to €25.46 billion. These estimates represented increases of 16.39% and 20.50% compared with the base-case estimates obtained with the opportunity cost method. Employing the willingness-to-accept value yielded even

higher cost estimates (€31.62 billion–€36.00 billion), indicating increases of 64.57% and 80.73% above the base-case estimates.

Applying the 126-h weekly cap minimally affected the cost estimates. Omitting this cap resulted in increases of 2.01%–2.51% from the opportunity cost base-case estimates and 2.75%–3.11% from the proxy good base-case estimates. This meagre effect was expected, considering the limited number of cases that required the cap.

The adjustment of informal care time, which involved deducting lost paid-work time, led to a modest reduction in the base-case estimates of total opportunity cost. The analysis placed the potential overestimation at 3.20% or 4.55%, depending on whether the friction cost or human capital approach was used to calculate indirect (productivity) costs (see Table 4.C.1 in Appendix 4.C).

Finally, the estimated cost of presenteeism among caregivers in 2019 was €1.79 billion (M = €352). When included in the proxy good estimate, the total cost increased by 5.93%. The same figure rose to 8.17% when presenteeism was factored into the opportunity cost estimate, contributing to 7.55%–18.45% of the total and indirect (productivity) costs, respectively. None of the sensitivity analyses significantly distorted the distribution of cost components in either the opportunity cost method or the proxy good method.

4.5. Discussion

4.5.1. Main Findings

Our study estimated the number of adult informal caregivers in the Netherlands at 5.1 million in 2019, indicating a prevalence rate of approximately 36% among the country's adult population. These estimates align with previous research and suggest a 16% increase in the number of caregivers and a 4-percentage point increase in prevalence since 2016 (de Boer et

al., 2020). A significant factor contributing to this trend is the country's rapidly expanding population of older adults (≥ 65 years), which grew by 7.4% between the two years (Statistics Netherlands, 2023d).

Furthermore, this study estimated the total costs of informal care in the Netherlands in 2019 to range between €17.50 billion and €30.13 billion, depending on the methods used to estimate informal care time and indirect (productivity) costs. These figures highlight the substantial economic burden of informal care on Dutch society. To contextualise these figures, the estimated annual cost of informal care in 2019 accounts for 2.15%–3.71% of Dutch GDP in the same year (€813 billion). Interestingly, these costs are of a similar magnitude to those of public spending on LTC (2.67% of GDP) and nearly half of that on education (5.20% of GDP) (Statistics Netherlands, 2020a, 2022a). To put these economic figures into individual terms, if the Dutch adult population were to shoulder the burden of informal care costs equally, an annual contribution of €1,230 to €2,119 per person would be required. Should these costs be apportioned through a uniform increase in income tax for all working adults in the Netherlands, their annual tax payments could rise by approximately €1,778 to €3,062. This increment would raise the tax burden by a margin equivalent to 5%–8% of the national average annual gross income (Statistics Netherlands, 2023b).

The study also estimated that Dutch informal caregivers provided approximately 1.55 billion hours of care in 2019, equivalent to 842,416 full-time working years (assuming 1,836 working hours per FTE). The economic value of this care was substantial, ranging from €12.4 billion to €23.4 billion, making it the primary contributor to informal care costs. Female caregivers accounted for approximately 58% of these costs, reflecting their provision of more caregiving hours than their male counterparts—a consistent finding in informal care research (Hanly & Sheerin, 2017; Peña-Longobardo & Oliva-Moreno, 2022). This disparity likely stems from longstanding societal and cultural norms that traditionally assign caregiving roles

primarily to women (Raiber et al., 2023). In the Dutch context, the labour market dynamics likely contribute further to this trend. More than 70% of employed Dutch women work part-time (Statistics Netherlands, 2023c), potentially affording them greater flexibility and more time for caregiving (Carrino et al., 2023; Rellstab et al., 2020).

Care-related out-of-pocket expenses in the Netherlands are notably modest. Dutch caregivers spent an average of €309 annually, significantly less than the €5,363 (PPP- and inflation-adjusted to 2019 Euro) reported for their American counterparts (Skufca & Rainville, 2021). This low out-of-pocket expenditure in the Netherlands may be attributed to available supportive measures, including comprehensive health insurance and pension plans, financial support (e.g., personal budget), and home care services (Government of the Netherlands, n.d.; Sowa-Kofta et al., 2021). Such measures can alleviate financial burdens on care recipients and their caregivers, particularly in areas of high expenditure, such as housing adaptations, healthcare services, specialised aids, and transportation (Duncan et al., 2020). Our analysis also reveals slight gender-based disparities in out-of-pocket expenses. While female caregivers collectively incur higher expenses, the mean individual expenditure for their male counterparts is about 13% higher (see Table 4.B.3 in Appendix 4.A). This difference may reflect societal norms that tend to cast men as primary financial providers, potentially tilting their contributions towards financial support (Kramer & Thompson, 2005). Furthermore, the existing wealth and income gap, favouring men (Statistics Netherlands, 2020b), seemingly facilitates their ability to shoulder these expenses. Considering the ongoing trend towards ageing in place and the anticipated rise in the number of individuals needing care, it becomes essential for future studies to continue examining these out-of-pocket expenditures.

Moreover, the study estimated the market productivity loss attributed to informal caregiving to range from €1.7 billion to €7.9 billion, depending on the valuation method. This loss corresponds to an estimated 45.1 million to 210.3 million hours of paid labour forgone,

tantamount to the productivity loss of 24,568 to 114,537 full-time jobs in 2019 (assuming 1,836 working hours per FTE). In examining the different forms of this productivity loss, we found that only 7% of non-working caregivers quit their previous jobs due to caregiving responsibilities. This finding is consistent with previous research demonstrating a modest negative correlation between labour force participation and informal care provision (Bauer & Sousa-Poza, 2015; Keating et al., 2013). Despite the relative infrequency of workforce exit among caregivers, it still carries a considerable economic burden. We estimated this burden to be between €1.10 billion and €3.42 billion, rendering it the second largest driver of indirect (productivity) costs (31%–43% of total indirect costs). The short time horizon of our study precluded accounting for the potential long-term societal costs of workforce exit. However, it is imperative to emphasise that withdrawal from the workforce, even temporarily, can have significant long-term consequences (Schulz, 2020). For example, caregivers who discontinue paid employment may face challenges when reintegrating into the labour market, such as overcoming gaps in employment history and addressing skill depreciation. These challenges can ultimately lead to reduced future employability and earning potential (Schmitz & Westphal, 2017). Consequently, further research is warranted to understand the long-term implications of workforce exit among caregivers and identify policy measures that can assuage these costs.

Despite being the most prevalent form of productivity loss, reducing work hours accounted for only a minor portion (8%–9%) of the total indirect (productivity) costs. Notably, the costs associated with this arrangement were 29%–43% higher for female caregivers, likely reflecting their greater involvement in part-time employment. This mode of employment offers the flexibility to adjust work hours in response to escalating caregiving demands rather than leaving the workforce (Heger & Korfhage, 2020; Josten et al., 2022).

By contrast, temporary leave emerged as the primary driver of indirect (productivity) costs, comprising 48%–61% of these costs. When combined with leaving the workforce

entirely, the total contribution to indirect (productivity) costs exceeded 90%. Remarkably, these costs were disproportionately higher for male caregivers, who faced 20%–31% higher costs than their female counterparts. This difference is partly attributable to the application of national gender-specific hourly labour costs, which are higher for men, in correspondence with the gender wage gap in the Dutch labour market (Statistics Netherlands, 2020b). Additionally, the average working hours for men are substantially higher, mainly owing to the higher incidence of full-time employment (Statistics Netherlands, 2022b, 2023c). Furthermore, the rigidity of traditional full-time employment arrangements limits men's capacity to adjust their working hours to meet caregiving needs (Heger & Korfhage, 2017). Consequently, male caregivers with increasing caregiving responsibilities are more likely to be forced out of employment than their female counterparts (Heger & Korfhage, 2020). This situation contrasts with women's experiences, who more often engage in part-time work and thus have the option of a more gradual reduction in work hours when balancing employment and caregiving duties.

This breakdown of indirect (productivity) costs suggests that reducing work schedules, instead of withdrawing from the workforce, can offer a mutually beneficial solution for caregivers and their employers. In addition to curtailing productivity loss, continuing to work, even with reduced hours, can bolster caregivers' emotional and social well-being (Arksey, 2003). Employers can also capitalise on this arrangement by retaining skilled employees, preserving institutional knowledge, maintaining workflow, and reducing recruitment and training expenses (Ireson et al., 2018; Kim et al., 2013).

In the Netherlands, national policies such as the Work and Care Act and the Flexible Work Act facilitate the balance between work and caregiving responsibilities (Vos et al., 2022). The latter enables employees to request flexible working conditions, including changes in work hours or locations (Hoefsmit et al., 2022). The Work and Care Act provides informal caregivers with short-term and long-term care leaves to assist a sick person. Short-term care leave extends

to twice the caregiver's weekly working hours, remunerated at 70% of their salary with a minimum wage guarantee. Long-term care leave, typically unpaid, can extend up to six times the caregiver's weekly hours (de la Porte et al., 2022). However, the utilisation of these leaves, particularly the long-term care leave, remains significantly limited (Van der Woude et al., 2016).

To further support informal caregivers in maintaining their employment, we propose expanding care leave in terms of duration, remuneration, and coverage. For example, in Belgium, unlike in the Netherlands, self-employed caregivers can receive care benefits for up to 12 months (De Wispelaere & Pacolet, 2017). Italy offers caregivers generous short-term (3 days per month) and long-term (up to 2 years) paid care leaves, with full salary and pension contributions (Jessoula et al., 2016). Additionally, new forms of flexible work arrangements, such as flexible weekly scheduling, team scheduling, and shift swapping, can accommodate the unpredictable and episodic nature of caregiving (Wieczorek et al., 2022). These arrangements are particularly beneficial for caregivers with lower wages, whose roles are often more rigidly tied to time and location (Watson & Swanberg, 2013). Lastly, it is crucial to raise awareness about existing work-care policies and flexible work arrangements, emphasising the value they bring to both caregivers and organisations.

4.5.2. Comparisons With Other Studies

Our research findings concur with those of analogous studies in different countries. However, caution is warranted when drawing such comparisons due to disparities in definitions of informal care, target demographics, methodologies, and cost components evaluated.

Internationally, our findings align with studies conducted in the United States and Australia. These studies deduce that informal care costs constitute up to 4% of GDP in both countries (Chari et al., 2015; Deloitte Access Economics, 2020). This finding is consistent with

our results for the Netherlands, underscoring the significant economic impact of informal care in various high-income countries despite differences in LTC systems.

A comparison with other European studies reveals both divergences and parallels. For example, the study by Ekman et al. (2021) estimates the opportunity cost of informal care in Sweden at 3.15% of GDP, which is 17% higher than our analogous figure for the Netherlands (derived using the human capital approach). This discrepancy is primarily due to their inclusion of factors such as presenteeism and disturbed sleep, which are not considered in our base-case analysis. Excluding these factors, Sweden's estimate decreases to 2.63% of GDP, nearly matching our estimate of 2.69%. Conversely, the Spanish study by Oliva-Moreno et al. (2019) reports costs per caregiver 10 to 17 times higher than in the Netherlands, signifying pronounced variations in care intensity consistent with the North–South informal care usage gradient in Europe (Barczyk & Kredler, 2019). The Irish study by Hanly & Sheerin (2017) offers a gender-specific analysis, showing that women account for two-thirds of informal care costs. This proportion is somewhat higher than in our study, where women account for about 58% of caregiving time costs. This gender disparity in our study diminishes when indirect and out-of-pocket expenses are considered, suggesting a relatively more equitable gender distribution of informal care costs in the Netherlands. The Dutch context, characterised by more developed formal care and higher part-time employment rates among women, seems to somewhat alleviate the informal care load and lessen the employment-care trade-offs for women.

Finally, the Ecorys report offers a direct comparison within the Netherlands (Blanken et al., 2021). Their €22 billion estimate, based on the opportunity cost method, initially appears congruent with our upper-bound estimate. However, a detailed analysis uncovers notable differences. The Ecorys estimate accounts for a subset of indirect (productivity) costs, specifically those related to reduced work hours, while our estimate encompasses a more comprehensive range of indirect costs. Aligning our estimate with the Ecorys methodology

results in a €14.7 billion figure, approximately 33% lower than the Ecorys estimate. A key strength of our study lies in using individual-level data, allowing for a precise estimation of the full spectrum of informal care costs. On the contrary, the Ecorys report relied exclusively on data from published reports and articles, which did not offer sufficient detail to capture the full scope of informal care costs. Furthermore, our study adheres to the Dutch guidelines for economic evaluations in healthcare, ensuring the comparability and interpretability of our findings (Versteegh et al., 2016; Zorginstituut Nederland, 2016). Specifically, we applied the friction cost approach to estimate indirect (productivity) costs and sourced relevant unit costs from the Dutch costing manual (Hakkaart-van Roijen et al., 2015).

4.5.3. Limitations

This study has certain limitations that should be acknowledged. First, the study did not account for the non-economic costs and benefits that may result from changes in caregivers' physical, social, and emotional well-being (Tarricone, 2006). Although recent literature increasingly focuses on these costs and benefits (Brouwer et al., 2005; Krol et al., 2015), they are still often omitted from cost analyses due to challenges in measurement and valuation (Jo, 2014; van Exel et al., 2004). While the importance of these costs and benefits cannot be overstated, we could not incorporate them due to a paucity of pertinent data.

The study also excluded transaction costs associated with informal care transfers (e.g., personal budget). Although these transfers do not represent real costs to society, they generate transaction costs that warrant consideration (Garrison et al., 2010; Hodgson & Meiners, 1982). However, estimating these costs is a formidable challenge due to the complex network of stakeholders involved, including municipalities, health insurers, and intermediaries responsible for implementing payments (Delsen, 2021). These transaction costs are also unlikely to constitute a significant portion of overall informal care costs. Therefore, we chose to omit them from our analysis.

Another aspect not covered in our study is the health care costs associated with informal caregiving. While informal caregiving can negatively affect caregivers' physical and mental health, evidence of its impact on health care utilisation is limited and inconsistent (Bom et al., 2019; Chan et al., 2013). For instance, a study by Shaffer & Nightingale (2020) using nationally representative data from the United States found no significant differences in the frequency or number of health care appointments between informal caregivers and non-caregivers. Another study by Van Houtven et al. (2005) showed higher drug utilisation rates among caregivers who provided intensive care to older people with dementia. However, the study concluded that the impact on informal care costs was minor and unlikely to have significant implications.

Another limitation relates to the measurement of informal care time. Research has indicated that informal caregivers may overestimate their care time (Landfeldt et al., 2019). This measurement bias can arise from the joint production of informal care and normal housework or the difficulty in distinguishing between the two (B. van den Berg et al., 2004). Despite the survey's instruction to exclude time spent on normal housework and usual care for housemates when reporting informal care time, some caregivers may have struggled to distinguish between these activities. This issue may have been particularly pronounced for caregivers living with the care recipient, providing high-intensity care, or caring for an extended period.

A further limitation lies in our approach to estimating out-of-pocket costs. Specifically, we capped these costs at €300 per month for the highest expense bracket due to the categorical nature of our data. This approach may have led to underestimating out-of-pocket costs for informal caregivers whose expenditures significantly exceeded this threshold. However, only 2% of caregivers reported expenses above the €300 cap. Therefore, while the potential for underestimation exists, its impact on our overall findings is likely minimal.

The final limitation pertains to the estimation of presenteeism costs. This estimation was based on responses to two survey questions about the frequency of distraction and the level of impaired concentration experienced by informal caregivers at work. We did not use standardised instruments such as the iMTA Productivity Cost Questionnaire or the Caregiver Indirect and Informal Care Cost Assessment Questionnaire (Bouwmans et al., 2015; Landfeldt et al., 2019). Consequently, our estimates for presenteeism costs should be interpreted cautiously, and they are presented separately from other costs in recognition of this limitation.

4.6. Conclusion

The shift towards LTC models in which informal caregivers play an increasingly larger role represents a significant change that demands careful consideration of its implications. While this change may appear fiscally responsible, our analysis indicates that it could carry substantial external costs borne by stakeholders and sectors beyond the intended targets of the policy. To our knowledge, this study is the first to provide nationally representative estimates of these external costs associated with informal care in the Netherlands.

We present compelling evidence for the immense value that informal care brings to society. Millions of caregivers make significant personal sacrifices, dedicating billions of euros' worth of time and resources to providing care. This infusion of resources into the Dutch LTC system effectively bridges existing care gaps by subsidising public-sector care provision. Absent these resources, the Dutch government would face a tremendous challenge in providing care for all those in need.

Despite its significant contributions, informal care remains largely excluded from national income accounts. This exclusion effectively renders these contributions invisible in standard macroeconomic frameworks, relegating informal care to the margins of economic policy discourse. This marginalisation jeopardises the sustainability and quality of informal

care and, inadvertently, undermines support for caregivers. Moreover, our findings demonstrate that informal care can adversely affect labour market productivity and supply. This impact reinforces the argument for integrating informal care into the analysis of labour market policy. Such integration could contribute to harnessing caregivers' potential in the labour market while preserving their invaluable caregiving roles.

The cost estimates we provide here can aid policymakers in adopting a comprehensive approach to the LTC system, which recognises the scarcity and value of all available resources—whether public, private, or informal. Such an inclusive outlook is crucial to inhibiting unproductive cost-shifting and determining the appropriate mix of LTC services that balances financial constraints with social welfare objectives.

Appendices

4.A. Unit Costs

Table 4.A.1. *Unit Costs of Resource Use*

	Unit of Measurement	Unit Cost (€)	Source
The opportunity cost of leisure time	Hour	8.02	The average value of one hour of non-business travel time savings for all surface modes (Kouwenhoven et al., 2014).
WTP for leisure time	Hour	10.34	(Verbooy et al., 2018)
WTA for leisure time	Hour	17.15	(Verbooy et al., 2018)
Work productivity loss[†]	Hour	34.18 (Women) 40.99 (Men)	(Hakkaart-van Roijen et al., 2015)
Household/domestic carer	Hour	15.14	(Hakkaart-van Roijen et al., 2015)

Note. Unit costs are presented in 2019 price levels. WTP = Willingness-to-pay. WTA = Willingness-to-accept.
[†]Lost paid-work time.

4.B. Gender-Specific Analysis

Table 4.B.1. *Weighted and Unweighted Descriptive Statistics by Gender for the Caregiver Sample*

Characteristic	Unweighted Caregiver Sample (N = 4,483)			Weighted Caregiver Sample (N = 14,222,458)		
	Male, N = 1,931	Female, N = 2,552	p-value[†]	Male, N = 7,029,007	Female, N = 7,193,451	p-value[‡]
Age in years, Mean (SD)	53.78 (17.23)	51.91 (16.90)	<0.001	47.70 (18.81)	48.79 (19.36)	0.008
Relationship status, n (%)			<0.001			<0.001
Married	1,232 (64%)	1,543 (60%)		3,381,312 (48%)	3,370,465 (47%)	
Divorced	144 (7%)	224 (9%)		584,658 (8%)	739,413 (10%)	
Widow	49 (3%)	142 (6%)		199,105 (3%)	608,818 (8%)	
Never been married	506 (26%)	643 (25%)		2,863,932 (41%)	2,474,755 (34%)	
Highest level of education, n (%)			<0.001			0.001
Primary education	265 (14%)	308 (12%)		1,017,363 (14%)	1,066,667 (15%)	
Secondary education	793 (41%)	1,278 (50%)		2,973,607 (42%)	3,264,752 (45%)	
Tertiary education	797 (41%)	881 (35%)		2,724,218 (39%)	2,528,986 (35%)	
None of these	76 (4%)	85 (3%)		313,819 (4%)	333,046 (5%)	
Employment status[§], n (%)			<0.001			<0.001
Not employed or retired	412 (24%)	705 (30%)		1,313,109 (20%)	1,865,477 (29%)	
Part-time	427 (24%)	1,313 (55%)		1,630,422 (25%)	3,471,435 (53%)	
Full-time	912 (52%)	369 (15%)		3,564,875 (55%)	1,175,812 (18%)	
Not in the labour force[¶]	180	165		520,601	680,727	
Hours of work per week[††], Mean (SD)	34.97 (13.01)	25.35 (11.01)	<0.001	34.95 (13.34)	25.90 (11.67)	<0.001

[†]Wilcoxon rank sum test; Pearson's chi-squared test.
[‡]Wilcoxon rank-sum test for complex survey samples; chi-squared test with Rao & Scott's second-order correction.
[§]Employment status refers to the employment status of the respondent during the year prior to the survey. Working full-time is defined as working 36 or more hours per week, and working part-time is defined as working less than 36 hours per week.
[¶]Individuals aged 76 years or older were considered out of the labour force.
[††]The number of working hours of employed respondents (n = 3,021).

Table 4.B.2. *Weighted Summary of Cost Items by Gender*

Cost Item	Male, N = 2,261,174	Female, N = 2,813,183
Direct cost items		
Hours of care per week (uncapped), Mean (SD)	7.11 (14.50)	8.08 (17.81)
Hours of care per week (capped), Mean (SD)	6.94 (12.86)	7.71 (14.94)
Hours of care per week (capped), n (%)		
Less than 5 hours	1,511,820 (67%)	1,765,868 (63%)
Between 5 and 15	526,875 (23%)	769,627 (27%)
Greater than 15	222,479 (10%)	277,689 (10%)
Duration of informal care (weeks per year), Mean (SD)	41.12 (17.56)	40.77 (17.78)
Monthly out-of-pocket costs, n (%)		
No out-of-pocket costs	1,146,038 (57%)	1,488,931 (60%)
Less than €50	399,101 (20%)	506,819 (20%)
Between €50 and €100	259,695 (13%)	299,595 (12%)
Between €100 and €200	100,522 (5%)	114,033 (5%)
Between €200 and €300	36,077 (2%)	38,552 (2%)
Greater than €300	54,922 (3%)	33,064 (1%)
Missing (unweighted)	229	303
Indirect (productivity) cost items		
Prolonged cessation of work, n (%)		
No	458,713 (92%)	760,249 (94%)
Yes	39,791 (8%)	50,171 (6%)
Temporary cessation of work, n (%)		
No	1,482,876 (95%)	1,683,237 (94%)
Yes	81,259 (5%)	107,143 (6%)
Reduction of working hours, n (%)		
No	1,487,176 (91%)	1,672,701 (89%)
Yes	139,413 (9%)	202,470 (11%)
Distraction at work, n (%)		
Rarely or never	1,202,902 (74%)	1,407,076 (75%)
Monthly	138,573 (9%)	147,702 (8%)
Weekly	158,296 (10%)	195,298 (10%)
Daily	78,789 (5%)	78,583 (4%)
Refusal	48,029 (3%)	46,512 (2%)
Missing (unweighted)	638	928
Less concentration at work, n (%)		
No, not at all	1,233,372 (76%)	1,392,387 (74%)
Yes, a bit	322,162 (20%)	392,784 (21%)
Yes, very much	31,285 (2%)	38,378 (2%)
Refusal	39,771 (2%)	51,622 (3%)
Missing (unweighted)	638	928

Note. Percentages may not add up to 100% due to rounding. Indirect (productivity) cost items were assessed only among subjects aged 16 to 75 years who combined work and care in the year preceding the survey.

Table 4.B.3. *Total Annual Costs of Informal Care Based on the Opportunity Cost Method by Gender*

		Human Capital Approach				Friction Cost Approach			
		Male		Female		Male		Female	
Domain	**Cost item**	**Costs (€)**	**Mean (€)**	**Costs (€)**	**Mean (€)**	**Costs (€)**	**Mean (€)**	**Costs (€)**	**Mean (€)**
A. Direct costs of informal care									
A.1	Informal care time	5,249,018,308	2,321	7,157,003,660	2,544	5,249,018,308	2,321	7,157,003,660	2,544
A.2	Out-of-pocket expenses	748,464,127	331	820,903,817	292	748,464,127	331	820,903,817	292
Sub-total		5,997,482,435	2,652	7,977,907,477	2,836	5,997,482,435	2,652	7,977,907,477	2,836
B. Indirect (productivity) costs									
B.1	Reduction of work hours	297,817,653	132	424,543,468	151	120,410,803	53	154,800,908	55
B.2	Temporary cessation of work	2,054,409,388	909	1,707,791,525	607	1,183,023,580	523	962,894,103	342
B.3	Prolonged cessation of work	1,940,463,162	858	1,475,879,618	525	625,385,210	277	475,692,719	169
Sub-total		4,292,690,203	1,898	3,608,214,611	1,283	1,928,819,594	853	1,593,387,729	566
Total societal costs		10,290,172,638	4,551	11,586,122,088	4,119	7,926,302,029	3,505	9,571,295,206	3,402

Note: Percentages may not add up to 100% due to rounding.

Table 4.B.4. *Total Annual Costs of Informal Care Based on the Proxy Good Method by Gender*

		Human Capital Approach				Friction Cost Approach			
		Male		Female		Male		Female	
Domain	**Cost item**	**Costs (€)**	**Mean (€)**	**Costs (€)**	**Mean (€)**	**Costs (€)**	**Mean (€)**	**Costs (€)**	**Mean (€)**
A. Direct costs of informal care									
A.1	Informal care time	9,909,122,368	4,382	13,511,026,422	4,803	9,909,122,368	4,382	13,511,026,422	4,803
A.2	Out-of-pocket expenses	748,464,127	331	820,903,817	292	748,464,127	331	820,903,817	292
Sub-total		10,657,586,495	4,713	14,331,930,239	5,095	10,657,586,495	4,713	14,331,930,239	5,095
B. Indirect (productivity) costs									
Sub-total		2,875,508,307	1,272	2,269,754,301	807	949,209,637	420	751,311,293	267
Total societal costs		13,533,094,802	5,985	16,601,684,540	5,902	11,606,796,132	5,133	15,083,241,532	5,362

Note: Percentages may not add up to 100% due to rounding.

4.C. Sensitivity analysis

Table 4.C.1. *Total Annual Costs of Informal Care Based on the Opportunity Cost Method (Adjusted Informal Care Time)*

Domain	Cost item	Human capital approach			Friction cost approach		
		Costs (€)	Mean (€)	Share of total costs, %	Costs (€)	Mean (€)	Share of total costs, %
A. Direct costs of informal care							
A.1	Informal care time	11,409,925,050	2,249	55%	11,845,675,266	2,334	70%
A.2	Out-of-pocket expenses	1,569,367,944	309	8%	1,569,367,944	309	9%
Sub-total		12,979,292,994	2,558	62%	13,415,043,210	2,643	79%
B. Indirect (productivity) costs							
B.1	Reduction of work hours	722,361,121	142	3%	275,211,711	54	2%
B.2	Temporary cessation of work	3,762,200,914	741	18%	2,145,917,683	423	13%
B.3	Prolonged cessation of work	3,416,342,780	673	16%	1,101,077,929	217	7%
Sub-total		7,900,904,815	1,556	38%	3,522,207,323	694	21%
Total societal costs		20,880,197,808	4,115		16,937,250,533	3,337	

Note: Percentages may not add up to 100% due to rounding.

Chapter 5

Projecting the Demand for Informal Care in Six European Countries From 2024 to 2074: A Microsimulation Modelling Study

5. Projecting the Demand for Informal Care in Six European Countries From 2024 to 2074: A Microsimulation Modelling Study

Abstract: Europe has experienced a steady increase in its older adult population over recent decades. This demographic shift has intensified the demand for long-term care (LTC). Consequently, European LTC systems have become increasingly reliant on informal care to support this age group. However, the continued ageing of the population raises concerns about the sustainability of this reliance. This study addresses the knowledge gap concerning future informal care needs by projecting the demand for informal care among individuals aged 50 to 100 over the next five decades in Germany, Greece, Italy, the Netherlands, Poland, and Sweden. We utilise individual-level data from the Survey of Health, Ageing and Retirement in Europe (SHARE) and employ a time-inhomogeneous Markov multi-state model (MSM) within a microsimulation framework. The projections indicate an initial increase in the population of older adults, followed by a gradual decline and eventual contraction by 2074. Sweden is an exception, with its population of older adults stabilising after an initial surge. The demand for informal care is projected to rise in Germany, Greece, and Italy, peaking in the 2050s and 2060s before gradually declining towards 2074. In contrast, Poland and Sweden exhibit a continuous increase in demand, while the Netherlands experiences a sharp rise until the early 2050s, followed by moderate growth. By 2074, the increase in informal care demand is projected to range from 11% in Greece to 64% in the Netherlands. Dependency prevalence and the utilisation rate of informal care are expected to rise across all countries. Additionally, the average age of informal care recipients is projected to increase by 6 to 8 years by 2074. These projections provide crucial insights for policymakers, aiding the development of robust policies and legislative measures to improve the sustainability of LTC systems against demographic change.

5.1. Introduction

Over the past two decades, Europe has witnessed a steady increase in the number and proportion of its older population (Michel et al., 2017). Between 2001 and 2022, the population aged 50 or older grew by 32%, with the oldest old demographic group (aged 85+) increasing by 85% in size and 78% in proportion (Eurostat, 2024c). Since the prevalence of dependency typically rises with age, these demographic changes have significantly heightened the demand for LTC (Holly, 2010).

In response to this ageing population, LTC systems across Europe have shifted towards models of care where informal caregivers play an increasingly vital role in assisting older adults with everyday tasks and social participation (Verbakel, 2018b). While this shift may temporarily alleviate pressures on formal LTC systems, it raises critical concerns about sustainability in the face of ongoing population ageing (Ribeiro et al., 2022).

Demographic projections underscore the urgency of these concerns. According to Eurostat, the population aged 50 or older is expected to expand by 16%, rising from 183 million in 2019 to 211 million by 2050. Remarkably, the population aged 85 or over is projected to grow most, increasing by 115% from 12.5 million to 26.8 million. Meanwhile, the population under 50 is projected to shrink by 13% during the same period (Eurostat, 2024f).

These projected demographic shifts are expected to place unprecedented demands on LTC systems, which are already grappling with workforce shortages and financial constraints (Geerts et al., 2012; Lis et al., 2023). Consequently, informal caregivers are likely to shoulder a progressively greater share of responsibilities. However, the simultaneous decline in the younger population and the economic costs of informal caregiving cast serious doubt on the long-term sustainability of continued reliance on informal care (M. Murphy et al., 2023; Ranci

& Pavolini, 2013). Adding to these challenges is a critical knowledge gap regarding the informal care resources required to meet growing care demands (Mosca et al., 2013).

This chapter addresses this gap by projecting the demand for informal care among individuals aged between 50 and 100 in six selected European countries over the next five decades. To this end, we leverage individual-level data on LTC from the Survey of Health, Ageing and Retirement in Europe (SHARE) and integrate a microsimulation model with a time-inhomogeneous Markov multi-state model (MSM). These projections will equip policymakers with essential data to craft effective care policies and establish resilient LTC systems capable of tackling the challenges posed by imminent demographic shifts. Furthermore, this forward-looking information can guide rational resource allocation across the LTC sector, ensuring that investments target areas of the greatest need and adapt to evolving care demands. Understanding future demands is also key to enhancing support services for caregivers and care recipients, potentially redefining service design and delivery.

5.2. Literature Review

Despite broad consensus on the challenges posed by the rising demand for LTC, evidence on the level of resources required to meet these future demands remains relatively scarce. The Personal Social Services Research Unit (PSSRU) developed a macrosimulation model to project future demands for LTC among older people in England for the period 2005–2041 (R. Wittenberg et al., 2008). The projections indicated substantial increases, with demand for formal home care, residential care, and informal care rising by 102%, 139%, and 102%, respectively. Subsequent updates to the model, covering the period 2015–2035, projected increases of 75%, 78%, and 63% for these respective types of care (Wittenberg & Hu, 2015). Using the same methodology, Geerts et al. (2012) projected LTC demands in Germany, the Netherlands, Spain, and Poland for the period 2010–2060. Their findings showed that in

Germany and the Netherlands, demand for residential and formal home care is likely to grow steadily until peaking in the 2050s, followed by a gradual decline. By the end of the projection period, residential care is estimated to rise by 102% in Germany and 200% in the Netherlands, while formal home care is expected to increase by 79% and 116%, respectively. The demand for informal care in these countries is projected to follow a similar trajectory, peaking in the 2050s, yet rising more modestly by 2060—51% in Germany and 66% in the Netherlands.

The macrosimulation approach in these studies has long been used to produce population projections (Matias et al., 2022). In its simplest form, this approach divides the population into groups according to specific characteristics (e.g., gender and age), assuming that individuals within each group are homogeneous. Calculations are then repeatedly performed on these groups over successive time intervals to evaluate how the size of each group evolves over time (Van Imhoff & Post, 1998). While simplifying the modelling process, the homogeneity assumption inherent in this approach remains a limitation as it disregards the heterogeneity within each group. Although introducing more characteristics can somewhat mitigate this limitation, it also increases the number of groups, potentially making the model unwieldy (Comas-Herrera et al., 2004).

Another limitation of the macrosimulation approach is the challenge of incorporating parameter uncertainty into future projections (Van Imhoff & Post, 1998). Parameter uncertainty relates to the fact that the model's input parameters are subject to uncertainty as to their true value (Briggs et al., 2006). This is because these parameters are typically estimated using statistical inferences drawn from empirical data, not from definitive knowledge of their 'true' values. Therefore, ideally, a projection model should provide not only the expected (mean) outputs but also the uncertainty surrounding these outputs (Hunink et al., 2014). Though theoretically feasible, quantifying the impact of combined uncertainty around input parameters

on the outputs of macrosimulation models requires complex methods. Consequently, parameter uncertainty is generally disregarded altogether in these models (Van Imhoff & Post, 1998).

Microsimulation models overcome these limitations by offering a flexible approach to incorporate heterogeneity and parameter uncertainty into future projections (Koerkamp et al., 2011). These models operate at the individual level, simulating the life course of each individual within a heterogeneous sample (Salonen et al., 2021). This individual-level approach accommodates heterogeneity by allowing state transitions to be influenced by a broad array of individual attributes, with no restrictions on the variable types defining these attributes (e.g., categorical or continuous). With respect to parameter uncertainty, Monte Carlo probabilistic sensitivity analysis (PSA) can be used to propagate input parameter uncertainties through these models to quantify the level of confidence in outputs. Another key advantage of microsimulation models lies in their generation of rich output of simulated individual event histories, which can be aggregated in various ways to estimate a wide range of population-level outcomes. This flexibility in aggregation stands in contrast with macrosimulation models, where the aggregation scheme becomes fixed once the model is specified (Van Imhoff & Post, 1998).

A key element in developing a microsimulation model is the specification of its parameters. This process relies on two fundamental components: data sources, which supply the necessary information, and a statistical model, which processes these data to estimate the input parameters required for the microsimulation model (Gampe et al., 2007). The optimal data source for parameter specification in microsimulation models is event history data, which typically provides individual longitudinal records detailing the timing of the specific event(s) of interest (Steele, 2005). However, these data are costly to collect and are not widely available. An alternative, more accessible source is panel surveys. In these surveys, data are collected at predefined, discrete points in time, known as panel waves. Each participant is repeatedly

observed during these waves, and information related to the event of interest is recorded (Andreß et al., 2013). This data framework leads to what is known as interval censoring, where the interval between waves during which the event of interest occurs is known, but the exact time of occurrence is not (Prataviera et al., 2023). Although panel data offer detailed information on event occurrences and the factors influencing them (Harding et al., 2017), their interval-censored nature poses analytical challenges, necessitating specialised techniques (Leffondré et al., 2013).

The MSM technique is recognised as an effective method for deriving input parameters for microsimulation models from panel data (Bongers et al., 2016). MSM, a generalisation of traditional survival analysis, offers a flexible framework that facilitates modelling state transitions and assessing the impacts of associated factors (Putter et al., 2007).

MSMs can be evaluated in either discrete or continuous time (Soares & Canto e Castro, 2012). Discrete-time MSMs partition time into fixed intervals, permitting only one transition at either the beginning or end of each interval. This representation of time is particularly apt for evenly spaced longitudinal data, where time intervals between two successive assessments remain consistent across subjects (Cao et al., 2016). Nonetheless, real-world panel data often exhibit irregular time intervals between observations and interval-censored state transitions, which may occur at any point within these intervals rather than strictly at their boundaries (Commenges, 2002). Discrete-time models are, therefore, often ill-suited for panel data, as the subjective selection of interval lengths may introduce biases that could distort the estimation of time spent in each state (Machado & van den Hout, 2018). In contrast, continuous-time MSMs permit a continuous progression of time, thus obviating limitations on the occurrence and timing of state transitions between observations. Furthermore, these models are well-equipped to handle interval-censored data (van den Hout, 2016).

Beyond the discrete versus continuous time distinction, MSMs are further classified based on assumptions regarding the time dependence of transitions. Commonly, these models employ the Markov assumption, positing that future state transitions depend on history solely through the current state (Asanjarani et al., 2022). The time-homogeneous Markov model is widely used within this framework, particularly for analysing interval-censored data. This model assumes constant transition hazards over time, an assumption that, while simplifying statistical modelling, often proves to be unrealistic and overly restrictive (Rahman et al., 2018).

Time-inhomogeneous Markov models, on the other hand, relax the assumption of constant hazards by allowing transition hazards to vary as a function of time and, potentially, additional explanatory covariates (Kapetanakis et al., 2013) . These models are, therefore, not Markovian in the strict sense, as state transitions depend not only on the current state but also on the current time and values of additional covariates. This flexibility enables more realistic modelling of processes where transition hazards are likely influenced by time-dependent factors, such as those typically observed in disease progression and ageing (van den Hout, 2016).

A commonly employed specification of time-inhomogeneous Markov models is the piecewise-constant hazard model, wherein hazards are assumed to remain constant within specified intervals but may vary between them (Ocañ-Riola, 2005). Van den Hout (2016) proposes two approaches for defining piecewise-constant hazards. The first approach, the Piecewise Constant Hazard Model, specifies interval-specific hazard parameters for each state transition. This model offers significant flexibility by permitting hazards to vary independently across intervals without conforming to a specific parametric form. Although this flexibility facilitates capturing complex hazard patterns, it also complicates extrapolation beyond the observed data due to the absence of a predefined parametric form describing how hazards evolve over time. Additionally, this model incurs higher complexity, especially when managing

numerous intervals, each with separate hazard rates. The second approach, the piecewise-constant approximation, mitigates these limitations by adopting a predefined parametric shape to govern hazard changes between intervals. This approach simplifies the model by eliminating the need to specify interval-specific hazard parameters; instead, it only defines the parameters for the parametric shape, resulting in a parsimonious piecewise-constant approximation of a parametric model. This approximated parametric model also facilitates efficient extrapolation of hazards beyond the observed time points.

5.3. Methods

5.3.1. Data

The data used in this chapter come from the Survey of Health, Ageing and Retirement in Europe (SHARE), release 8.0.0. SHARE is a cross-national longitudinal survey that collects information on the health, socio-economic status, and social and family networks of noninstitutionalised Europeans aged 50 or older (Börsch-Supan et al., 2013). The survey commenced in 2004, and up until the writing of this chapter, data were available from eight waves and two additional COVID-19 surveys, covering the period from 2004 to 2022. A detailed description of the SHARE methodology is documented elsewhere (Bergmann et al., 2019, 2024; Bergmann & Börsch-Supan, 2021; Börsch-Supan et al., 2008; Börsch-Supan & Jürges, 2005; Malter & Börsch-Supan, 2013, 2015, 2017; Schröder, 2011).

The sample for this study was derived from waves 1–8, spanning the period from 2004 to 2020 (SHARE-ERIC, 2022a, 2022b, 2022c, 2022d, 2022e, 2022f, 2022g, 2022i). Wave 3 was excluded as it focused on life history and did not gather information about the variables of interest. Six of the 28 countries participating in SHARE were selected for the final sample: Germany, Greece, Italy, the Netherlands, Poland, and Sweden. These countries, also selected for the ENTWINE iCohort Study, represent the different welfare regimes in Europe: Southern

(Italy and Greece), Continental (Germany), Scandinavian (Sweden), Eastern (Poland), with the Netherlands representing a unique regime that blends elements of both Continental and Scandinavian regimes (Eikemo et al., 2008; Widding-Havneraas & Pedersen, 2020).

The analysis excluded individuals residing in residential care facilities, those interviewed only once, and those outside the specified age range of 50 to 100 years. Consequently, the total analytical sample comprised noninstitutionalised individuals aged 50–100 with observed values for all variables of interest in at least two waves. Pairwise deletion was employed to handle missing data, given that the proportion of missing data was less than 3% for all variables. Deaths were reported by proxy respondents in end-of-life interviews, which collected information about the year preceding each respondent's death, including the exact date of death. Data from the COVID-19 surveys were utilised solely to supplement the information on death (Scherpenzeel et al., 2020; SHARE-ERIC, 2022h, 2022j).

To account for unreported deaths among participants with unknown vital status in each wave, we applied the life-table correction method developed by Bergmann et al. (2020) for SHARE data. In each wave, mortality rates were assigned to these participants based on age-, sex and country-specific data from Eurostat for the corresponding year of that wave (Eurostat, 2024d, 2024a, 2024b). These assigned rates were aggregated to estimate the total number of unreported deaths within the group. Under the assumption that individuals with higher mortality rates were more likely to die, participants were classified as deceased in descending order of their assigned rates until the estimated total of unreported deaths for that wave was reached.

5.3.2. Variables and Measures

Covariates. The analysis considered the following covariates: age at the wave of data collection, sex, and educational level (1 = highest educational attainment is tertiary education

according to the International Standard Classification of Education 1997 [ISCED-97], 0 = otherwise). Sex and education were measured at baseline. Age was measured in years.

Dependency Level. The dependency level was measured by assessing difficulties in performing Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). In SHARE, the ADL and IADL scales are slightly modified compared to their original forms (Katz, 1983; Lawton et al., 1969). The ADL scale included six basic everyday self-care activities: dressing, walking, bathing, eating, getting in or out of bed, and toileting. The IADL scale included seven instrumental activities: using a map, preparing meals, shopping, making telephone calls, taking medications, doing housework, and managing finances. Additional IADL items were added after wave 6; however, these items were excluded from the analysis to maintain consistency in measurement across waves (Gruber et al., 2024). For reasons of sample size, this study combined the two indices, ADL and IADL, into a dichotomous variable distinguishing whether the respondent had limitations in at least one index or not (1 = presence of limitations, 0 = absence of limitations).

Receipt of Informal Care. Informal care was defined as non-professional support provided by caregivers residing either inside or outside the household. Informal care from outside the household included personal care, household assistance, and administrative support received within the 12 months prior to the interview or since the last interview. For individuals living with a spouse or partner, the designated family informant reported on extra-household support without specifying which household member was the recipient. When personal care assistance was reported, this support was attributed to the partner experiencing difficulties with ADL. For extra-household assistance with household and administrative tasks, it was assumed that both partners benefited from this aid.

Informal care provided within the household in the SHARE questionnaire was limited to personal care, excluding support with household and administrative tasks. To address this exclusion, we imputed within-household assistance for these tasks using the algorithm proposed by Pommer et al. (2007). Specifically, if a respondent living with others reported difficulties in ADL or IADL and received assistance with household or administrative tasks but did not receive care from external caregivers or formal providers, it was inferred that household members provided this assistance.

Respondents were classified as informal care users if they reported receiving assistance with personal care, household tasks, or administrative tasks, regardless of whether the assistance was provided by caregivers residing inside or outside their households.

5.3.3. Multi-state Model

A continuous-time MSM is defined as a model for a stochastic process $(Y(t), t \in T)$, which at any given time t occupies one state out of a finite set of states $S = \{1, \dots, K\}$ (Hougaard, 1999). The evolution of the process—both the subsequent state and the timing of transitions—is governed by transition hazards (J. Zhang et al., 2023). These transition hazards quantify the instantaneous risk of moving from one state to another at any given moment (Jackson, 2011). The model is fully characterised by defining transition-specific hazard regression models for every pair of states $r, s \in S$, between which a transition is possible according to the specified multi-state process (van den Hout, 2016). Transition hazards can be functions of the process time t or a set of time-invariant or time-varying covariates $x(t) = \left(x_1(t), \dots, x_p(t)\right)$. Time dependency, i.e., how the transition hazard changes over time, can be specified via the baseline transition hazard $\lambda_{rs}(t)$ by assuming a parametric shape (Machado & van den Hout, 2018). Various approaches to modelling how covariates $x(t)$ influence the transition hazards have been proposed in the literature. The most prominent is the proportional

hazards model with a log-linear functional form, which estimates the hazard rate at a given time as the product of a baseline hazard function and an exponential function of the covariates. Mathematically, this hazard regression model is represented as:

$$\lambda_{rs}\big(t|x(t)\big) = \lambda_{rs.0}(t) \cdot exp\big(\beta_{rs}^{\top} x(t)\big) \quad \textbf{(5.1)}$$

where $\lambda_{rs.0}(t)$ denotes the baseline hazard for the transition from state r to state s, $x(t) = \Big(x_1(t), \ \dots \ , \ x_p(t)\Big)^{\top}$ represents the covariate vector without an intercept term, and $\beta_{rs} = \big(\beta_{rs.1}, \ \dots \ , \ \beta_{rs.p}\big)^{\top}$ is the vector of regression coefficients describing the effects of the covariates $x(t)$ on the hazard of transition $r \rightarrow s$.

We applied a five-state time-inhomogeneous continuous-time Markov MSM with four transient states and one absorbing state to estimate the transition rates at which individuals move between these states. See Figure 5.1 for a representation of the five-state model. The five mutually exclusive and exhaustive states were defined based on dependency in ADL and IADL (i.e., independent or dependent) and the use of informal care (i.e., user or non-user):

1. Independent/Informal care non-user (State 1): Individuals independent in both ADL and IADL who did not receive informal care.
2. Independent/Informal care user (State 2): Individuals independent in both ADL and IADL who received informal care.
3. Dependent/Informal care non-user (State 3): Individuals with at least one limitation in ADL or IADL who did not receive informal care.
4. Dependent/Informal care user (State 4): Individuals with at least one limitation in ADL or IADL who received informal care.
5. Dead (State 5): The absorbing state from which no further transitions are possible.

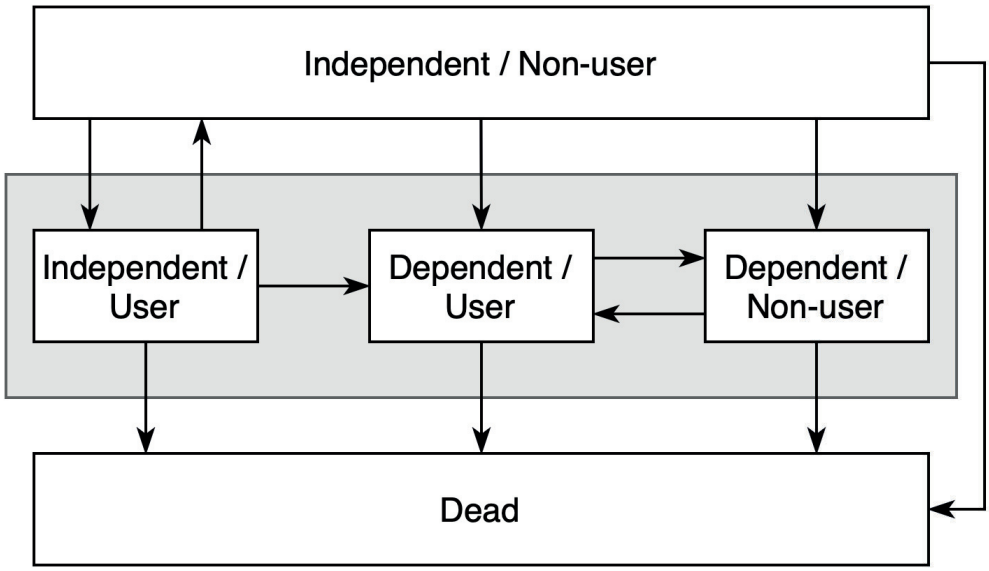


Figure 5.1. *Representation of the Five-State Model*

We specified 11 allowable instantaneous state transitions. See Figure 5.1 for a representation of the permitted transitions between the states. Dependency in ADL or IADL was considered irreversible since SHARE recorded only difficulties in these activities that lasted more than three months. Conversely, the model allowed bi-directional transitions between different states of informal care use (user vs non-user). A direct transition from 'Independent/informal care user' to 'Dependent/informal care non-user' was deemed unrealistic and, therefore, disallowed. If an individual was observed to make such a transition, it was assumed that they passed through the intermediary state 'Dependent/informal care user' but that the path was not completely observed. Individuals could remain in the same state without transitioning, and progression to death was possible from any state.

In the presence of interval censoring, estimating time-dependent MSMs becomes challenging and requires specialised methods. This challenge is particularly pronounced in models that include backward transitions, as is the case in our model. To account for the

potential time dependency in our model, we adopted the piecewise-constant approximation approach proposed by van den Hout (2016). This approach enables the modelling of age-dependent transition hazards by incorporating age as a time-varying covariate within the log-linear framework presented in Equation 5.1. The age covariate is handled in a piecewise-constant manner, assuming that transition hazards remain constant within each observed time interval but may vary piecewise-constantly between intervals (as age progresses) according to a predefined parametric shape for the baseline hazard.

The Gompertz hazard model is the most commonly used model to describe demographic ageing, as age-specific mortality and age-related frailty typically follow an exponential trajectory with age (Bokov et al., 2017; Pletcher, 1999). Assuming a Gompertz baseline hazard for the transition $r \rightarrow s$ and no covariates other than age (A), the model in Equation 5.1 simplifies to a smooth Gompertz model for the hazard of the transition $r \rightarrow s$, expressed as:

$$\lambda_{rs}(A) = exp(\lambda_{rs.0} + \xi_{rs}A) \quad \textbf{(5.2)}$$

In this model, only the parameters $\lambda_{rs.0}$ and ξ_{rs} need to be estimated, resulting in a parsimonious piecewise-constant approximation of the Gompertz hazard model. The dependency on age in Equation 5.2 defines a monotonic transition hazard that either increases or decreases exponentially with age, following a Gompertz function.

In addition to age, we simultaneously examined the effects of sex and educational level on transitions between the five states using pooled data from the six countries studied. The analysis included sex, education and country-specific fixed effects as covariates for all transitions. The model is specified as:

$$\lambda_{rs}(A) = exp(\lambda_{rs.0} + \xi_{rs}A + \beta_{rs.1}sex + \beta_{rs.2}education + \beta_{rs.3}NL + \beta_{rs.4}IT + \beta_{rs.5}PL + \beta_{rs.6}SE + \beta_{rs.7}EL) \quad \textbf{(5.3)}$$

where $\beta_{rs.3}$, $\beta_{rs.4}$, $\beta_{rs.5}$, $\beta_{rs.6}$ and $\beta_{rs.7}$ are the country fixed effects for the Netherlands, Italy, Poland, Sweden, and Greece, respectively, with Germany serving as the reference country in our analysis.

The impact of educational level on transitions within the same dependency status (i.e., $1 \rightarrow 2$, $2 \rightarrow 1$, $3 \rightarrow 4$, and $4 \rightarrow 3$) was found to be statistically insignificant. As a result, we excluded educational level from these specific transitions by imposing the constraint $\beta_{rs.2} = 0$. This adjustment led to a more parsimonious model with a lower AIC value compared to the initial specification. To evaluate country-specific heterogeneity in the influence of covariates on state transitions, we conducted a separate analysis for each country. These individual analyses yielded results consistent with those from the pooled data, showing no significant discrepancies and only slight variations in parameter estimates. Therefore, we opted for the pooled analysis approach to provide more generalisable insights within a broader European framework while achieving greater statistical efficiency.

We used the R package 'msm' (version 1.7.1) to estimate the model and derive the age-dependent transition hazards and hazard ratios of the covariates (Jackson, 2011, 2023). Age was used as the time scale and was centred at 50 (the minimum age in the data) to facilitate computations without altering the results. Time in-homogeneity was verified by comparing the log-likelihood of our model with that of a time-homogeneous model. We also compared our model in Equation 5.3 against an alternative time-dependent model with a Weibull baseline hazard for all transitions. The alternative model was estimated using the 'nhm' package in R

software (Titman, 2023). The Gompertz hazard model yielded a lower AIC than the Weibull hazard model.

The advantages of our approach were fourfold. First, it allowed for the estimation of hazard rates for each transition and each individual profile. Second, it addressed the interval-censored nature of SHARE data, where the exact timing of state transitions was unknown. Third, it facilitated the combined analysis of data from all countries studied, irrespective of when or how frequently data were collected in those countries. Finally, it enabled the analysis of individuals with varying observation patterns, such as differing numbers of observations and varying time intervals between them. Thus, the only restriction imposed was that respondents needed to have been interviewed at least twice to provide sufficient data for observing any state transitions.

5.3.4. Microsimulation

We operationalised an open population microsimulation model to simulate individual trajectories of dependency and informal care utilisation across the countries under study from January 1, 2024, up to December 31, 2073. The starting cohort consisted of individuals aged 50 to 99 at the start of the simulation. By adopting an open population framework, the model allowed for the successive integration of new 50-year-old cohorts into the model population. The model follows each individual from their entry until either their passing or reaching the age of 100. The model does not incorporate immigration or emigration. This decision was motivated by the substantial uncertainty associated with projecting immigration/emigration patterns in the context of ageing populations. Individuals in the simulation have four attributes: age, sex, educational attainment and country. The following steps were employed to construct the synthetic population for the microsimulation model:

1. The base population for the model was derived from the 2024 Eurostat population data, which provides aggregate population counts by age and sex for the six countries under investigation. The data was disaggregated to generate individual-level records for the demographic segment of interest, specifically individuals aged between 50 and 99.
2. The day and month of birth of each individual in the disaggregated data were randomly assigned, taking into account the age and leap years.
3. Given the absence of educational attainment data within the Eurostat dataset, we resorted to probabilistically imputing this attribute using data from the sixth wave of the SHARE survey. Age, sex, and country-specific proportions for tertiary educational attainment were calculated. A binomial distribution model, parameterised by these proportions, was then employed to assign the educational attainment level to each individual record, either having attained tertiary education or not.
4. A multinomial regression model, parameterised on SHARE data with age, sex, education, and country as covariates, was used to calculate the predicted probabilities for each state for each individual record. Starting states were then assigned stochastically.
5. Given the extensive size of the resulting dataset, a stratified sampling approach was adopted to ensure both representativeness and computational efficiency. Stratification criteria included age, sex, and country, with a target sample size of 10% of the total population aged 50–99 in 2024 for each country.
6. Eurostat's population projection data from 2025 to 2074 for the six countries under investigation were used to create fresh samples of individuals turning 50 years old each year. These samples were subsequently incorporated into the model population annually after the first year. The construction of these fresh samples followed the same methodology employed in constructing the base population.

Age-dependent transition rates and hazard ratios were directly obtained from the MSM for all allowable state transitions. By incorporating these rates into the microsimulation model, we were able to simulate the trajectory of dependency and informal care utilisation for each individual based on their attribute profile. At the start of the simulation process, two random variables are generated for each individual. The first is the exit/waiting time, which is drawn from the specified distribution for the state of origin with the parameter of the total exit rate from that state (the sum of transition rates for all permissible transitions from the state of origin). The destination state is determined by the second random variable u, sampled from a uniform distribution $U[0,1]$. The chosen destination state depends on the cumulative probabilities at time t: if $u < p_1(t)$, the first state is selected; if, $p_1(t) \leq u < p_1(t) + p_2(t)$, the second state is chosen; and if, $p_1(t) + p_2(t) \leq u < p_1(t) + p_2(t) + p_3(t)$, the third state is selected, and so forth. After establishing the destination states and transition times for all individuals, those transitioning to the 'dead' state are removed from the simulation. The simulation clock then advances to the nearest upcoming transition time, identified by the shortest waiting time among all individuals. This iterative process continues until the simulation clock exceeds the predetermined end time.

5.3.5. Probabilistic Sensitivity Analysis

We conducted a PSA to assess the joint uncertainty in model parameters using a second-order Monte Carlo simulation with 1,000 replicates. Each model parameter was assigned a probability distribution that reflects the uncertainty in its true value. For each simulation, a set of model parameter values was randomly sampled from these distributions, and the model was executed using this unique set as inputs, resulting in a unique set of model outputs. This procedure was repeated 1,000 times, thereby generating distributions of model outputs. These distributions were subsequently used to derive 95% predictive intervals. These intervals

provided quantitative measures of the uncertainties in the outputs, arising from uncertainties in the input model parameters (YHEC, 2016).

In our model, the input parameters governing the transition between the defined states are the transition hazards estimated by the MSM. To account for the uncertainty around these transition hazards, we simulated 1,000 transition hazard matrices from the asymptotic multivariate normal distribution implied by the maximum likelihood estimates and covariance matrix of the log transition hazards and covariate effects (Jackson, 2023).

5.4. Results

5.4.1. Descriptive Findings

Table 5.1 summarises the characteristics of our sample, categorised by country, education level, and birth cohort for both men and women. Gender differences were evident in tertiary education attainment, with a higher proportion of men (23%) than women (17%) having completed tertiary education. Overall, 19% of respondents had attained tertiary education. Italy and Germany recorded the highest number of participants, reflecting their participation in SHARE from its inception. On average, women participated in 3.7 waves, while men participated in 3.5 waves.

Table 5.1. *Sample Characteristics by Education Level, Cohort of Birth, and Country for Men and Women. Individuals Aged 50–100*

Characteristic	**Women**, N = 17,160	**Men**, N = 14,984	**Overall**, N = 32,144
Country, n (%)			
Germany	3,218 (19%)	2,956 (20%)	6,174 (19%)
Greece	3,131 (18%)	2,494 (17%)	5,625 (17%)
Italy	3,463 (20%)	2,985 (20%)	6,448 (20%)
Netherlands	2,361 (14%)	2,152 (14%)	4,513 (14%)
Poland	2,093 (12%)	1,777 (12%)	3,870 (12%)
Sweden	2,894 (17%)	2,620 (17%)	5,514 (17%)
Tertiary education, n (%)			
No	14,325 (83%)	11,586 (77%)	25,911 (81%)
Yes	2,835 (17%)	3,398 (23%)	6,233 (19%)
Cohort of birth, n (%)			
1900-1929	1,701 (10%)	1,489 (10%)	3,190 (10%)
1930-1939	3,344 (19%)	3,416 (23%)	6,760 (21%)
1940-1949	5,239 (31%)	4,956 (33%)	10,195 (32%)
1950-1959	5,219 (30%)	4,116 (27%)	9,335 (29%)
1960-1969	1,657 (10%)	1,007 (7%)	2,664 (8%)
Average n of participations in SHARE waves, Mean	3.7	3.5	3.6

The age distributions at baseline and during follow-up are depicted in Figure 5.2. The median age at baseline was 63.3, rising to 67.6 during follow-up. The median follow-up interval was 2.2 years, as illustrated in Figure 5.2.

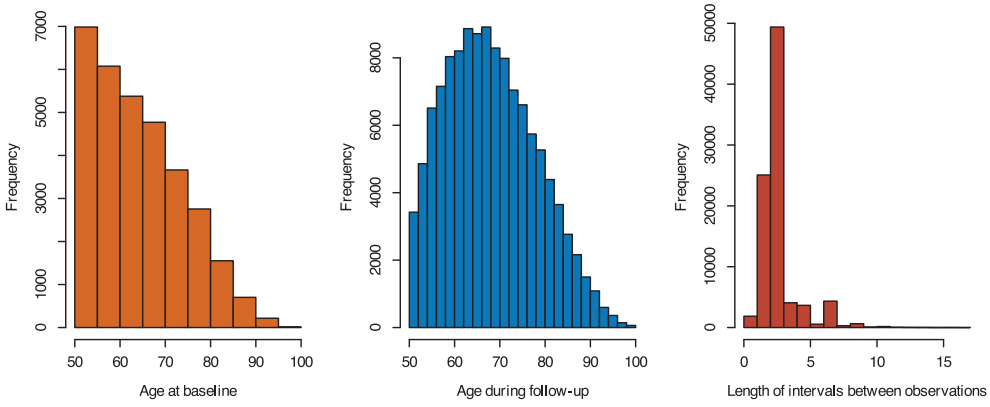


Figure 5.2. *Distribution of Age and Follow-up Intervals*

Table 5.2 reports the prevalence of dependency in ADL or IADL across countries, birth cohorts and education levels for each of the eight waves of the SHARE survey, disaggregated

by gender. The results demonstrated a consistent educational and birth-cohort gradient, with individuals having tertiary education and those from younger cohorts showing lower prevalence rates of dependency. Among both genders, the Netherlands reported the lowest dependency, whereas Poland recorded the highest. While these patterns were evident across both genders, women consistently reported higher rates of dependency than men. This gender disparity was most pronounced in the most disadvantaged groups (low education and 1900–39 birth cohort). Notably, Greece and Italy exhibited the largest gender disparities in dependency rates.

Table 5.2. *Prevalence of Dependency in ADL or IADL in Each SHARE Wave by Country, Education Level, and Cohort of Birth for Men and Women. Individuals Aged 50–100*

			Wave1	Wave2	Wave4	Wave5	Wave6	Wave7	Wave8
Men	**Country, %**	Germany	13.5%	17.7%	25.4%	17.8%	22.4%	38.7%	31.9%
		Greece	12.4%	13.8%	–	–	19.0%	24.4%	26.1%
		Italy	12.2%	18.1%	18.6%	20.1%	21.9%	34.0%	31.1%
		Netherlands	12.4%	15.3%	16.7%	17.3%	–	–	23.8%
		Poland	–	29.3%	34.6%	–	37.1%	47.6%	35.3%
		Sweden	13.6%	17.1%	21.5%	16.4%	21.5%	28.2%	28.4%
	Tertiary education, %	No	14.3%	19.8%	24.1%	20.6%	25.1%	36.1%	33.4%
		Yes	7.5%	11%	14.7%	10.6%	14.7%	22.5%	18.9%
	Cohort of birth, %	1900-1929	31.1%	42.6%	53.7%	43.9%	61.1%	82.2%	76.7%
		1930-1939	13.1%	21.6%	28.6%	28.0%	36.9%	46.6%	51.4%
		1940-1949	7.5%	12.3%	17.2%	15.2%	21.0%	28.8%	28.8%
		1950-1959	6.0%	8.6%	13.6%	11.4%	13.7%	20.7%	21.1%
		1960-1969	–	–	3.1%	7.8%	9.4%	–	15.3%
Women	**Country, %**	Germany	18.1%	21.3%	27.2%	20.6%	25.9%	35.2%	35.0%
		Greece	27.1%	30.0%	–	–	29.9%	40.0%	37.3%
		Italy	22.2%	28.4%	29.8%	30.3%	31.9%	45.8%	40.2%
		Netherlands	18.4%	23.2%	25.7%	29.0%	–	–	33.6%
		Poland	–	36.9%	40.9%	–	42.6%	51.8%	36.8%
		Sweden	19.0%	23.9%	28.1%	22.6%	28.0%	37.9%	34.7%
	Tertiary education, %	No	23.1%	29.5%	32.0%	28.2%	33.5%	45.5%	39.4%
		Yes	10.6%	13.7%	19.0%	15.2%	16.2%	25.4%	24.7%
	Cohort of birth, %	1900-1929	47.9%	59.9%	66.5%	67.9%	77.4%	87.0%	86.8%
		1930-1939	23.7%	34.9%	42.6%	40.7%	55.9%	67.6%	68.0%
		1940-1949	12.9%	20.6%	25.3%	22.0%	29.5%	39.5%	38.3%
		1950-1959	9.7%	13.1%	18.1%	17.5%	19.0%	27.0%	26.8%
		1960-1969	–	–	8.3%	9.7%	9.5%	10.3%	17.3%

The prevalence of informal care use, categorised by country, birth cohort, and education and further segmented by gender, is detailed in Table 5.3. Individuals with higher education levels and those belonging to younger birth cohorts were found to use informal care less frequently. Italy recorded the lowest rates of informal care use among the countries analysed,

while Germany reported the highest. In terms of gender differences, women consistently utilised informal care more than men across all examined countries. Germany exhibited the lowest gender disparity in use rates, whereas Greece displayed the highest. The gender gap in care usage was also notably wider among individuals with lower educational levels and those born between 1900 and 1939.

Table 5.3. *Prevalence of Informal Care Use in Each SHARE Wave by Country, Education Level, and Cohort of Birth for Men and Women. Individuals Aged 50–100*

			Wave1	Wave2	Wave4	Wave5	Wave6	Wave7	Wave8
Men	**Country, %**	Germany	24.6%	27.6%	23.1%	22.2%	26.2%	32.3%	26.6%
		Greece	20.1%	18.2%	–	–	20.7%	17.4%	17.2%
		Italy	16.6%	19.0%	16.3%	15.6%	13.8%	18.1%	13.5%
		Netherlands	19.3%	22.4%	17.4%	14.9%	–	–	23.6%
		Poland	–	22.8%	16.0%	–	16.5%	17.3%	14.9%
		Sweden	22.5%	21.5%	14.9%	14.8%	19.9%	21.0%	22.7%
	Tertiary education, %	No	21.4%	22.5%	17.3%	17.2%	19.9%	20.3%	20.7%
		Yes	18.0%	18.2%	17.4%	17.2%	19.2%	19.5%	18.3%
	Cohort of birth, %	1900-1929	36.1%	38.4%	44.2%	36.2%	46.8%	59.8%	51.7%
		1930-1939	18.1%	22.1%	20.5%	20.9%	27.3%	30.0%	36.6%
		1940-1949	16.8%	18.1%	12.5%	14.0%	17.8%	16.0%	18.7%
		1950-1959	18.5%	17.0%	13.0%	15.2%	14.4%	11.5%	13.4%
		1960-1969	–	–	9.4%	17.0%	16.0%	–	14.3%
Women	**Country, %**	Germany	28.8%	32.9%	24.5%	23.5%	28.4%	32.5%	30.7%
		Greece	28.6%	25.5%	–	–	25.4%	24.2%	22.2%
		Italy	21.3%	22.1%	19.6%	20.0%	20.8%	23.0%	17.8%
		Netherlands	24.7%	26.9%	20.4%	20.7%	–	–	26.4%
		Poland	–	27.2%	18.3%	–	21.4%	23.6%	17.8%
		Sweden	28.0%	27.4%	20.5%	19.2%	24.9%	26.1%	25.7%
	Tertiary education, %	No	27.0%	27.0%	20.6%	21.6%	25.2%	26.0%	24.0%
		Yes	23.1%	25.2%	19.7%	18.4%	20.7%	19.4%	22.3%
	Cohort of birth, %	1900-1929	50.1%	52.5%	51.5%	49.8%	62.5%	65.4%	66.7%
		1930-1939	27.1%	30.3%	26.9%	27.2%	40.8%	42.5%	47.3%
		1940-1949	18.6%	21.2%	16.2%	16.7%	21.4%	22.2%	23.7%
		1950-1959	18.8%	18.0%	13.4%	17.7%	16.4%	12.9%	15.8%
		1960-1969	–	–	9.5%	18.3%	16.2%	14.9%	13.7%

Table 5.4 presents the frequencies of pairs of consecutive states in the data. For each state r and state s, these frequencies represent the number of instances an individual had an observation in state r followed by an observation in state s. Zero frequencies indicate impermissible state transitions (see Figure 5.1).

Table 5.4. *Frequencies of Pairs of Consecutive States*

	To (State *s*)						Total
	Independent/ Informal care non-user	Independent/ Informal care user	Dependent/ Informal care non-user	Dependent/ Informal care user	Dead	Censored	
From (State *r*)							
Independent / Informal care non-user	23,387	3,074	1,643	973	1,786	14,612	45,475
Independent / Informal care user	2,778	1,360	0	690	473	2,741	8,042
Dependent / Informal care non-user	0	0	4,557	1,573	1,092	2,477	9,699
Dependent / Informal care user	0	0	1,523	2,337	1,773	1,979	7,612
Censored	10,964	1,552	3,142	2,027	1,666	134	19,485
Total	37,129	5,986	10,865	7,600	6,790	21,943	90,313

Note. This table shows the number of times an individual had an observation in state *r* followed by an observation in state *s*.

5.4.2. Transition Rates and Hazard Ratios

Estimated baseline transition rates and covariate effects, as hazard ratios, with 95% confidence intervals (in parentheses), are presented in Table 5.5. Age was significantly correlated with all transitions, showing positive associations with dependency in ADL/IADL, utilisation of informal care, and mortality. Women independent in ADL/IADL exhibited an 11.7% increased risk of receiving informal care compared to their men counterparts. This effect, however, diminished after the onset of disability.

Furthermore, women not receiving informal care encountered a 33.1% higher risk of dependency compared to males, a contrast not observed among informal care recipients. As expected, the mortality risk was consistently higher in men, regardless of their dependency status or informal care utilisation. The influence of educational attainment was examined exclusively for transitions leading to dependency or death, revealing reduced risks for these transitions associated with higher educational levels.

Table 5.5. *Estimated Baseline Transition Rates and Covariate Effects as Hazard Ratios With 95% Confidence Intervals. Reference Country = Germany*

Transition	Baseline Transition Rate	Age	Woman	Education	Sweden	Netherlands	Italy	Greece	Poland
1 → 2	0.174 (0.154, 0.196)	1.016 (1.01, 1.021)	1.117 (1.014, 1.23)	– –	0.741 (0.648, 0.848)	0.809 (0.683, 0.957)	0.541 (0.464, 0.632)	0.232 (0.2, 0.271)	0.749 (0.468, 1.199)
1 → 3	0.043 (0.037, 0.049)	1.063 (1.057, 1.07)	1.331 (1.207, 1.467)	0.569 (0.492, 0.659)	0.838 (0.718, 0.979)	0.724 (0.599, 0.874)	0.877 (0.754, 1.02)	0.589 (0.49, 0.707)	1.132 (0.94, 1.364)
1 → 4	0.009 (0.005, 0.015)	1.213 (1.192, 1.234)	1.435 (1.126, 1.828)	1.106 (0.793, 1.543)	0.766 (0.441, 1.332)	0.499 (0.172, 1.446)	1.401 (0.814, 2.411)	3.839 (2.343, 6.292)	1.033 (0.424, 2.516)
1 → 5	0.026 (0.021, 0.033)	1.07 (1.061, 1.08)	0.533 (0.459, 0.62)	0.753 (0.611, 0.929)	0.757 (0.574, 0.997)	1.188 (0.9, 1.567)	0.786 (0.6, 1.03)	0.733 (0.553, 0.972)	2.077 (1.599, 2.699)
2 → 1	0.536 (0.471, 0.61)	0.986 (0.981, 0.991)	0.879 (0.797, 0.969)	– –	1.027 (0.892, 1.183)	1.013 (0.852, 1.204)	1.353 (1.156, 1.584)	0.466 (0.402, 0.542)	2.425 (1.571, 3.744)
2 → 4	0.16 (0.134, 0.19)	1.054 (1.046, 1.062)	0.991 (0.864, 1.136)	0.614 (0.507, 0.743)	0.817 (0.67, 0.997)	0.906 (0.726, 1.129)	1.132 (0.913, 1.403)	0.535 (0.417, 0.688)	1.568 (1.092, 2.252)
2 → 5	0.037 (0.02, 0.071)	1.093 (1.061, 1.126)	0.343 (0.207, 0.568)	0.919 (0.496, 1.702)	1.02 (0.506, 2.058)	1.808 (0.884, 3.7)	0.704 (0.249, 1.988)	0.772 (0.344, 1.73)	0.699 (0.162, 3.013)
3 → 4	0.316 (0.275, 0.364)	1.048 (1.041, 1.055)	1.096 (0.974, 1.233)	– –	0.655 (0.548, 0.782)	0.572 (0.458, 0.715)	0.643 (0.544, 0.759)	0.421 (0.345, 0.515)	0.559 (0.458, 0.682)
3 → 5	0.041 (0.028, 0.061)	1.104 (1.088, 1.122)	0.732 (0.578, 0.926)	0.954 (0.677, 1.345)	1.012 (0.64, 1.601)	1.881 (1.223, 2.893)	0.853 (0.542, 1.344)	1.012 (0.643, 1.593)	1.290 (0.819, 2.034)
4 → 3	0.222 (0.191, 0.259)	0.984 (0.979, 0.99)	1.003 (0.893, 1.126)	– –	1.151 (0.952, 1.391)	0.905 (0.727, 1.126)	1.106 (0.927, 1.32)	0.635 (0.522, 0.774)	1.049 (0.855, 1.287)
4 → 5	0.154 (0.135, 0.175)	1.06 (1.053, 1.067)	0.606 (0.547, 0.671)	0.803 (0.672, 0.958)	1.049 (0.887, 1.242)	1.011 (0.825, 1.239)	0.926 (0.791, 1.084)	0.825 (0.705, 0.966)	1.084 (0.903, 1.302)

The analysis also uncovered significant heterogeneity across countries. Residents of Germany had a markedly higher likelihood of receiving informal care than those in other countries, irrespective of dependency status. Furthermore, living in Poland correlated with an increased risk of dependency, particularly among informal care users. A striking observation was the nearly fourfold rise in the risk of dependency among individuals in Greece receiving informal care. Contrastingly, country-specific differences in mortality transitions were generally minor, with few exceptions. For instance, individuals in Greece and Sweden who do not receive informal care exhibited approximately 25% lower mortality risk than their counterparts in Germany.

5.4.3. Microsimulation Results

The microsimulation results are presented as graphs showing how the outputs of interest change over the simulation period. The locally weighted regression smoothing technique, commonly referred to as 'LOESS', is applied to projection data to better illustrate trends over time (Cleveland & Devlin, 1988).

Figure 5.3 illustrates the projected population trends of individuals aged 50–100 in the six countries from 2024 to 2074. With the exception of Sweden, all countries exhibit a pattern of initial population growth, peaking at different times throughout the projection period before a subsequent decline towards 2074. The growth rate varies significantly across countries. Italy and Greece are expected to reach their peak population sizes in the mid-2030s, followed by Germany and Poland in the mid-2040s and the Netherlands in the mid-2050s. The magnitude of growth also differs markedly, with Germany and Italy experiencing a near 4% increase at their peak, Greece and the Netherlands at 7% to 10%, respectively, and Poland witnessing a sizable 19% growth. Sweden, however, presents a unique trend, with its population aged 50–100 projected to increase by nearly 17% by 2050, after which it would stabilise. By the end of the projection period, the aged populations of Germany, Greece, and Italy are projected to shrink by 14%, 17%, and 24%, compared to their initial sizes in 2024. Conversely, the populations in the Netherlands, Poland, and Sweden are expected to grow, with the former two increasing by 3% and 5%, respectively, and Sweden by approximately 17%.

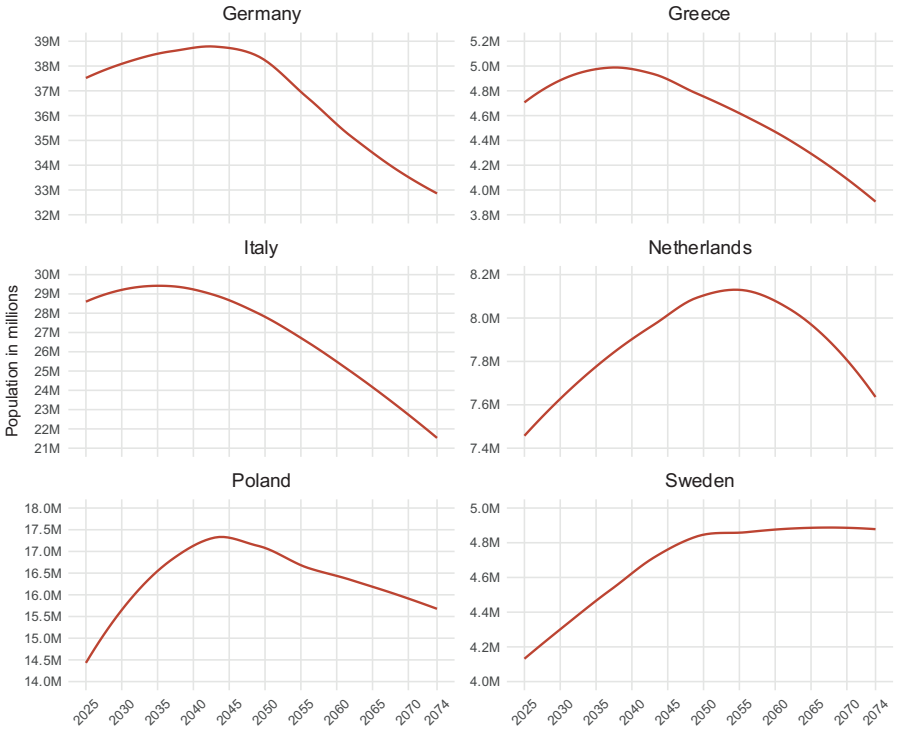


Figure 5.3. *Simulated Population Projections for Individuals Aged 50–100 in the Six Countries (2024–2074)*

Figure 5.4 delves deeper into these projections by segregating the data by gender and offering a comparative analysis with Eurostat's projections for the same demographic and period. This gender-specific breakdown reveals patterns of population change similar to those observed in the aggregate data, with the simulation projections closely aligning with Eurostat's figures (Eurostat, 2024e).

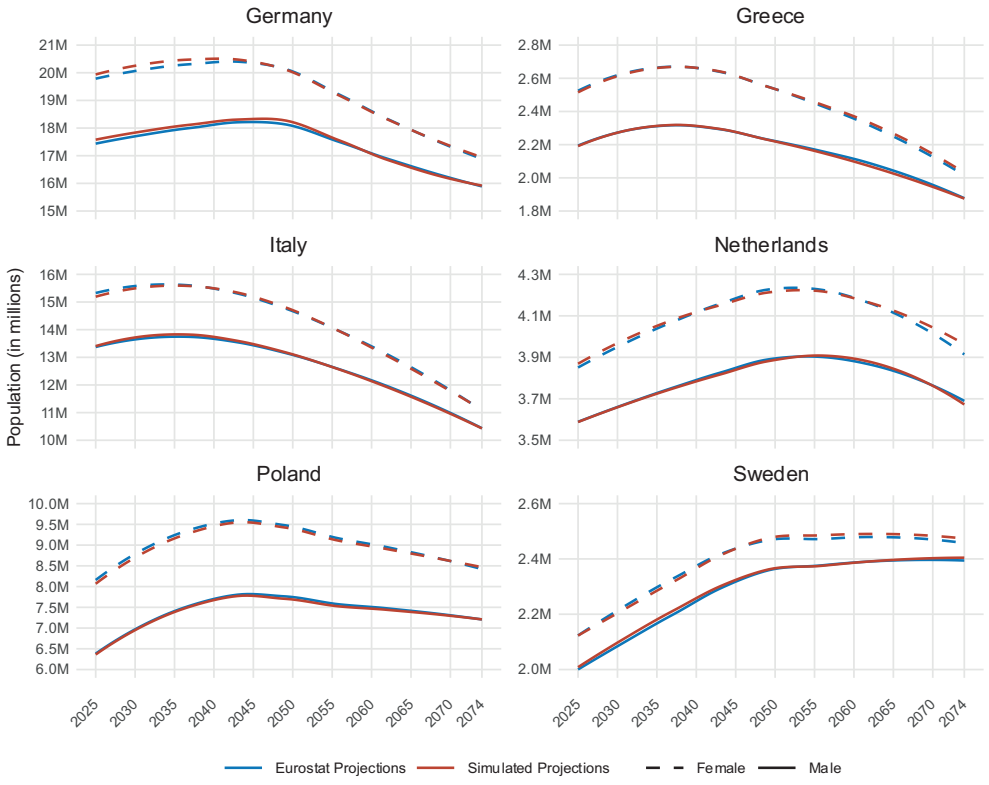


Figure 5.4. *Simulated vs. Eurostat Population Projections for Individuals Aged 50–100 by Gender in the Six Countries (2024–2074)*

Figure 5.5 depicts the projected demand for informal caregivers in the six countries from 2024 to 2074. Germany, Greece, and Italy exhibit a pattern of initial surge in demand, peaking in the early 2050s for Germany, the mid-2050s for Italy, and the early 2060s for Greece, before experiencing a significant decline towards 2074. Specifically, peak demands in these countries are projected to range from a 22% increase in Greece to a 47% increase in Italy relative to the base year. By the end of the projection period, Germany is expected to experience the highest relative increase in demand at 19%, followed by Italy at 15% and Greece at 11%. In sharp contrast, Poland and Sweden are projected to see a continuous upward trend in demand

throughout the projection period, with increases of approximately 47% by 2074. The Netherlands presents a distinctive trend, with a steep increase in demand until the early 2050s, followed by a period of moderate growth, culminating in a 64% increase from the base year by 2074—marking the largest increase among the studied countries.

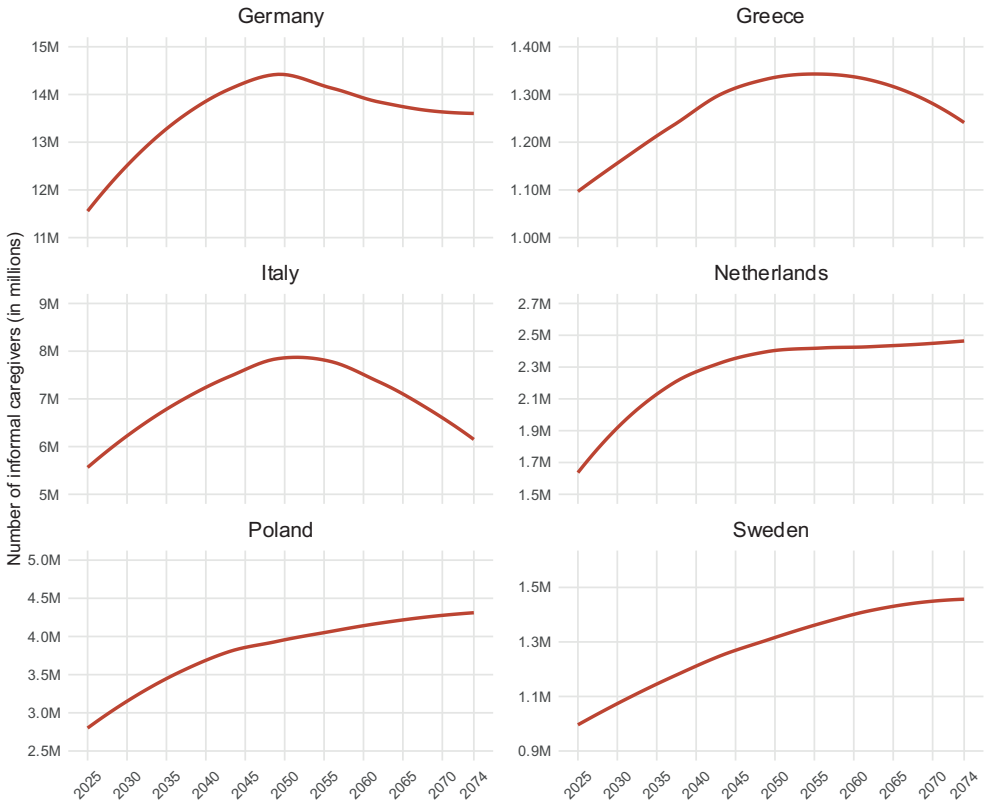


Figure 5.5. *The Projected Demand for Caregivers in the Six Countries (2024–2074).*

Figure 5.6 illustrates the projected prevalence rates of all defined states among the 50–100 age demographic across the six countries. In 2024, dependency prevalence rates range from 24% to 28% in all examined countries, except for Poland, where a significantly higher rate of 38% is observed. The prevalence rate of dependency is expected to increase steadily from 2024

to 2074 across the board. By 2050, a notable escalation in these rates is anticipated in the Netherlands, Germany, and Italy, with prevalence rates reaching 42%, 47%, and 48%, respectively. In contrast, Sweden and Greece are projected to experience a slightly lesser increase, with prevalence rates approximating 39%. Poland, presenting the highest initial dependency rate, is expected to witness the smallest relative increase, reaching 45%. By 2074, it is projected that over half of the population aged 50–100 in Germany and Poland (50% and 52%, respectively) will be dependent in ADL/IADL. Italy and the Netherlands are expected to exhibit similar trends, albeit to a lesser extent, with just under half of their populations becoming dependent in ADL/IADL (46%–48%). Prevalence rates in Greece and Sweden are also projected to rise, with around 43% of their populations becoming dependent in ADL/IADL.

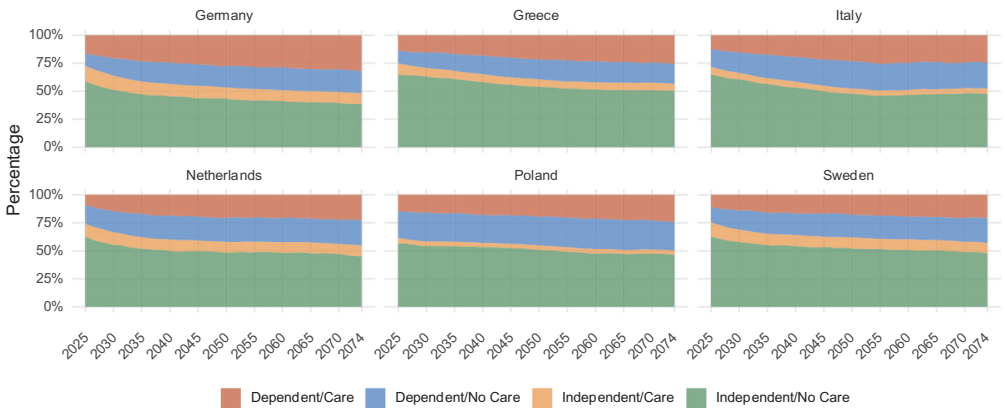


Figure 5.6. *Projected Prevalence Rates of All Defined States Among the 50–100 Age Demographic Across the Six Countries (2024–2074)*

Furthermore, the utilisation rate of informal care is projected to increase across all countries. Germany exhibits the highest prevalence of informal care usage in the base year at 30%. The prevalence rates among the 50–100 aged population in other countries vary from 20% in Italy to 24% in Greece and Sweden. By the midpoint of the projection period, it is

anticipated that approximately 38% of Germany's population, 24% of Poland's, and over a quarter of the population in the remaining countries will be receiving informal care. By the end of the projection period, Germany is anticipated to maintain the highest prevalence rate at 41%, while the remaining countries are expected to see slightly less than a third of their populations (28%–32%) receiving care.

Figure 5.7 delineates informal care projections by recipient dependency in ADL/IADL, contrasting the proportions of care directed towards dependent and independent receivers. This visualisation underscores a pronounced, steady rise in the fraction of care directed towards dependent recipients across all surveyed countries. This trend is particularly pronounced in Sweden, the Netherlands, and Germany, where the share of care provided to dependent individuals is expected to escalate from 45%, 45%, and 54% in 2024, to 64%, 68%, and 74% by 2050, and further to 70%, 70%, and 77%, respectively, by 2074. Greece, Italy, and Poland, starting from relatively high levels of informal care provision to dependent individuals (57%, 64%, and 74%, respectively), are projected to exhibit similar, albeit smaller increases, reaching remarkably elevated levels by 2074. Specifically, informal care for dependent individuals in Greece, Italy and Poland is projected to constitute 80%, 84%, and 87% of total informal care, respectively, by the end of the projection period.

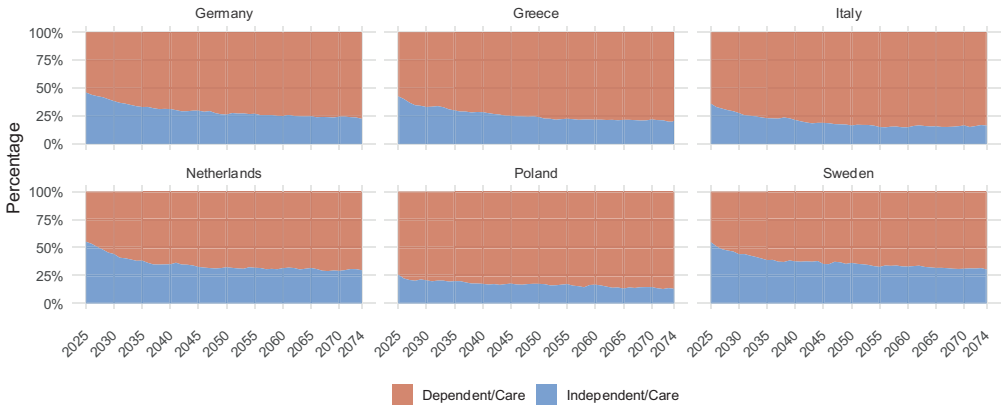


Figure 5.7. *Projected Percentages of Informal Care Provided to Dependent and Independent Recipients (2024–2074)*

Figure 5.8 depicts the projected mean age of informal care receivers across the projection period for each country. Initially, mean ages range from 69 years in the Netherlands to 74 years in Italy. By the end of the projection period, these averages are expected to rise by 6 to 8 years, reaching between 76 years in the Netherlands and 81 years in Greece.

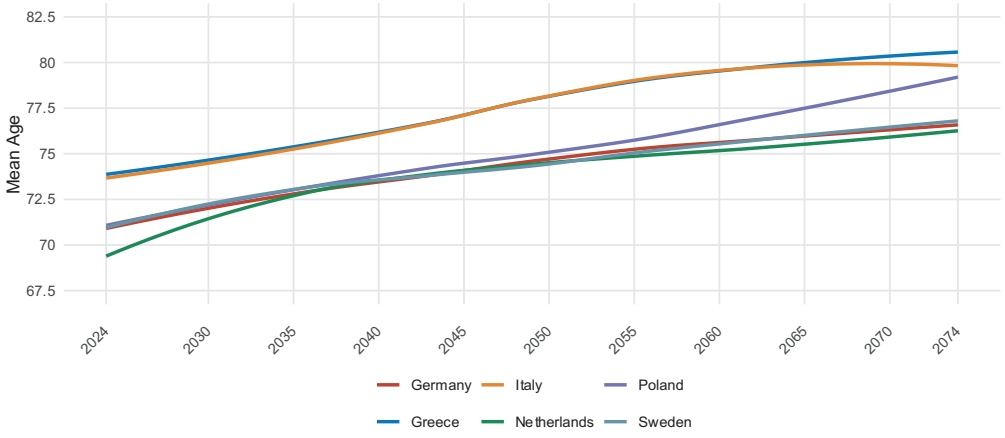


Figure 5.8. *Mean Age of Informal Care Receivers by Country (2024–2074)*

5.4.4. Probabilistic Sensitivity Analysis

Figure 5.9 presents the probabilistic projections for population trends of individuals aged 50–100 in the six countries. Deterministic projections are depicted with solid blue lines. Probabilistic median projections are shown as violet dot-dashed lines, with 95% prediction intervals represented by dashed red lines. These intervals demonstrate the uncertainty in the projections, delineating the range within which the predicted population totals for the specified age group are likely to fall with 95% probability. The probabilistic projections closely align with the deterministic projections across all countries, albeit with median probabilistic figures approximately 1% lower. The widening 95% prediction intervals across all countries indicate increasing uncertainty over time.

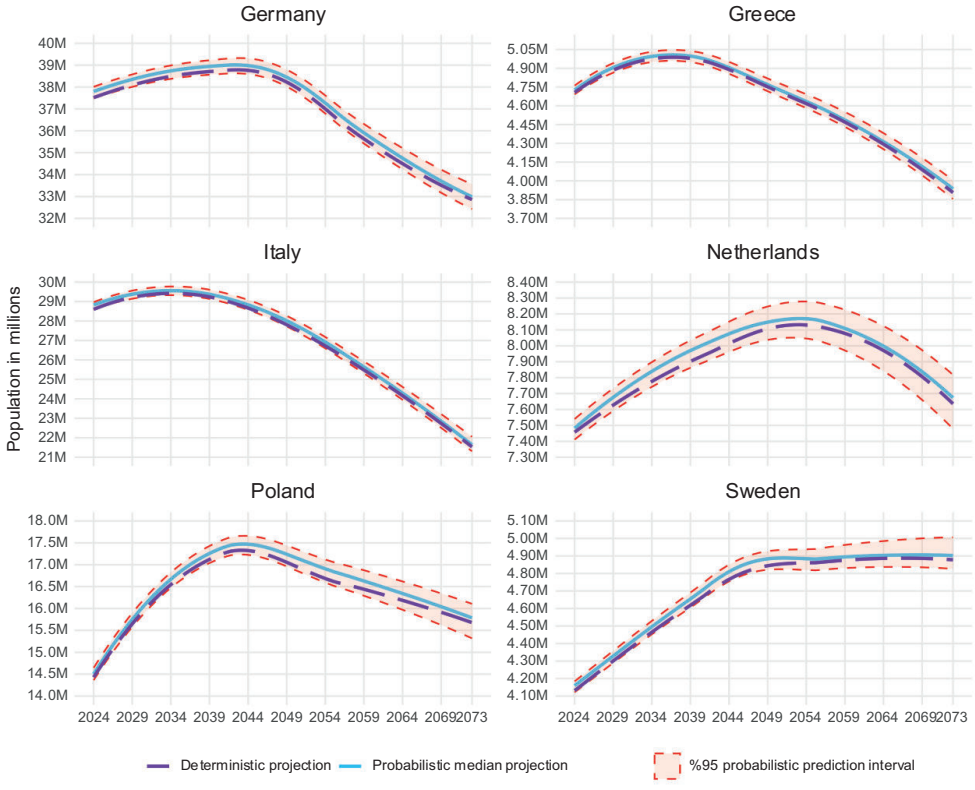


Figure 5.9. *Probabilistic Projections for Population Trends by Country (2024–2074)*

Figure 5.10 displays the probabilistic projections for the demand for caregivers in the six countries. These projections align with the trajectories suggested by deterministic projections, with median figures showing a slight deviation of about 1% lower. It is important to emphasise that these probabilistic projections do not provide more accurate estimates than their deterministic counterparts; rather, they aim to offer additional quantitative information to present a more comprehensive picture of prediction uncertainty.

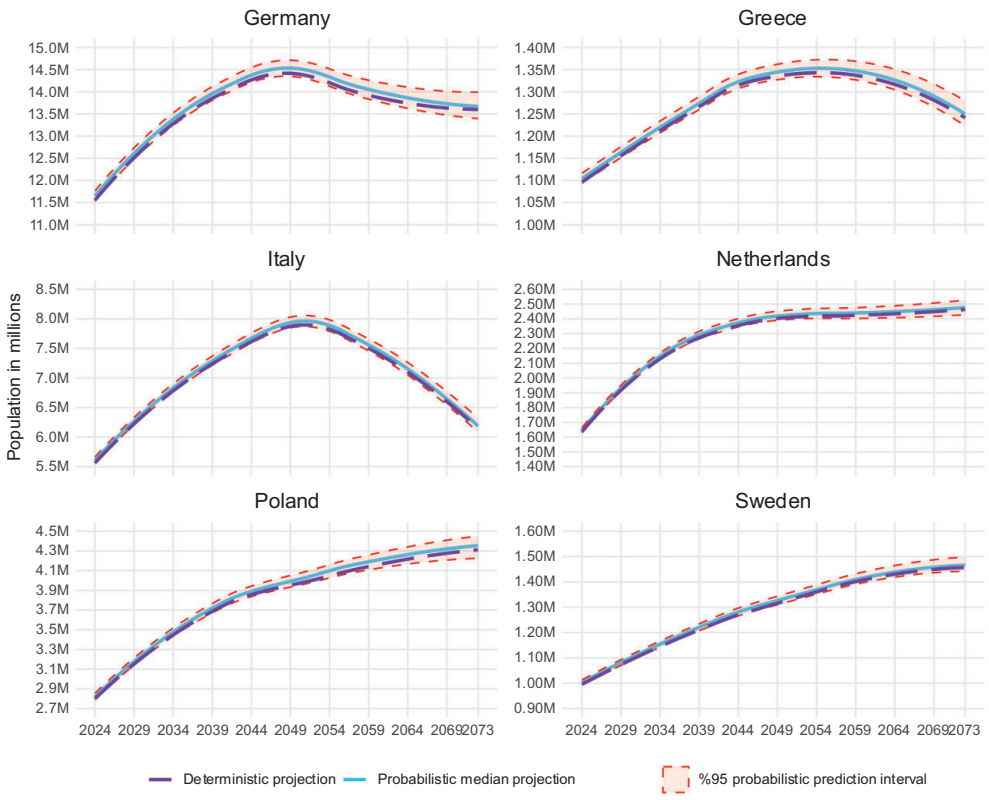


Figure 5.10. *Probabilistic Projections for the Demand for Caregivers by Country (2024–2074)*

5.5. Discussion and Concluding Remarks

Like many developed regions, Europe is currently experiencing a rapid ageing of its population. In this context, understanding the extent of LTC resources required to address the needs of older individuals is crucial. With a growing dependence on informal care across Europe, projecting future demands for such care is vital for policymakers tasked with devising proactive strategies, planning system designs, and directing investments. This chapter presents an innovative approach that employs multi-state modelling within a microsimulation framework to project the demand for informal care targeted at populations aged 50–100 in Germany, Greece, Poland, Italy, Sweden, and the Netherlands. This approach takes advantage of recent advancements in these techniques and leverages available multinational panel data—an invaluable asset for cross-country projection modelling.

Our main result is a projected increase in the demand for informal care over the next five decades across all examined countries. This rise is anticipated to be pronounced particularly in the near to intermediate term. By 2050, the increase in the demand for informal care is projected to range between 21% in Greece and 62% in the Netherlands relative to the base year. In absolute numbers, the study projects the number of informal care recipients in 2050 to total 1.3 million in Greece and Sweden, 2.4 million in the Netherlands, 4.1 million in Poland, 7.8 million in Italy, and 14.4 million in Germany.

Over the long term, the trend of increasing demand for informal care is expected to continue in Poland and Sweden and stabilise in the Netherlands, reaching 47%, 47% and 64%, respectively, by the end of the projection period relative to the base year. By contrast, this trend is expected to reverse post-peak in Germany, Greece, and Italy, with demand levels reducing by 8%, 9% and 21% by the end of the projection period, respectively, relative to the peak year. These three countries present a paradoxical scenario post-peak demand: despite a projected

decrease in the absolute number of older individuals requiring informal care, the proportion of the older population, particularly those of very advanced age, is projected to rise. Initially, the expected decline in the absolute number of older individuals requiring care after reaching peak demand may imply a potential reduction in caregiver demand. Nevertheless, this assessment oversimplifies the complexities inherent in the caregiving ecosystem. Recent projections from Eurostat for Greece, Germany, and Italy indicate that, during the post-peak demand period, the decline in the older population will be surpassed by a more significant decrease in the younger adult population (aged 18–49), with reductions of 10%, 19%, and 24%, respectively (Eurostat, 2024e). This demographic shift suggests that a diminishing pool of potential caregivers will be increasingly urged to support an older population that, although decreasing in absolute numbers, will constitute a larger proportion of the total population.

Another observation of equal importance is the persistent rise projected in the proportion of the population aged 50–100 requiring care across all countries over the next five decades. By the end of the projection period, this increase is estimated at 26% in Sweden, 34% in Greece, 38% in Germany, 39% in Poland, 52% in Italy, and 60% in the Netherlands, relative to the base year. This trend towards a higher prevalence of care needs points to an intensifying burden of care per capita. The situation is likely to be further compounded by the projected increase in the average age of care recipients. Although uncertainties remain regarding the future health trajectories of older adults (Marois & Aktas, 2021), it is reasonable to expect that the rising mean age of care recipients will correspond to more complex and intensive care needs due to heightened frailty and dependency.

In this context, promoting healthy lifestyles and implementing effective morbidity prevention programs should be considered integral components of a comprehensive policy to mitigate future care demands (H. Barrett et al., 2016; Vaquero-Abellan et al., 2022). There is an evident and pressing need to invest in ‘healthy ageing’ projects to enhance the overall well-

being of the older population and support their independence (Prasher et al., 2021). Another avenue of policy action is raising the population's education level. Our findings indicate a significant association between higher education levels and reduced likelihood of dependency. This association likely reflects the positive influence of education on income, access to information and healthcare, the adoption of healthier lifestyles, and other factors conducive to healthy ageing (Wagg et al., 2021).

We compare our results with the projections for Germany and the Netherlands by Geerts et al. (2012). For Germany, their projections indicate a 25% increase in the demand for informal care by 2050 relative to 2025, closely mirroring our projection of a 28% increase. However, their projections for the Netherlands suggest a 20% increase, substantially lower than our estimate of 62%. Despite these differences, the overall trend of rising demand for informal care over time remains broadly consistent between the two sets of projections for both countries.

In terms of absolute numbers, the figures reported by Geerts et al. diverge significantly from ours. They project the demand for informal care in Germany to be 3.4 million in 2025, increasing to 4.2 million by 2050—approximately one-third of our corresponding projections. The figures for the Netherlands are notably small, ranging from 140,000 to 165,000 over the same period, which is substantially lower than our estimates.

Several factors may explain these discrepancies. First, the projections by Geerts et al. are limited to the demand for informal care among individuals aged 65 or older, whereas our study include a broader age range, beginning at 50 years. Second, Geerts et al. base their projections on pooled data from the first and second waves of the SHARE Survey, collected between 2004 and 2007. Since then, the long-term care systems in both countries have undergone substantial reforms, significantly restricting eligibility for residential care and promoting informal care (Geyer & Korfhage, 2018). Furthermore, Geerts et al. confine informal

care to personal and nursing care, whereas our broader definition also encompasses household and administrative support. These additional forms of informal care are by no means insignificant, constituting real, substantive tasks and efforts.

Europe's evolving social and economic landscape adds further layers of complexity to the dynamics of informal care (Piróg, 2016). For example, the incidence of single-adult households in the EU (i.e., households consisting of a single adult, whether living with children or not) increased by 29.6% between 2009 and 2022 (Eurostat, 2023b). This trend is concerning from the perspective of informal care, especially since cohabiting spouses and partners have traditionally been the most significant source of such care in Europe (Bertogg & Strauss, 2020). Additionally, during the same period, there was a 30.7% rise in the number of single-adult households without children, who represents another crucial source of informal care. Regarding households with children, nearly half now have only one child (Eurostat, 2023b).

Further compounding these concerns is evidence suggesting a decline in residential proximity between older parents and their children over the years, primarily due to factors such as educational expansion and urbanisation (Kalmijn, 2021). The geographical distance between parents and their children remains a decisive factor affecting the receipt and extent of informal care (Schoeni et al., 2022). This is particularly true for tasks requiring direct contact, such as personal and instrumental support, which depend heavily on geographical proximity and regular face-to-face interaction (Isengard, 2013).

These societal shifts stress a looming challenge in the provision of informal care, which has traditionally been anchored within the immediate family framework (Zygouri et al., 2021). The ramifications of this shift are significant, underscoring the need for governmental intervention to support not only older people in need of care but also their caregivers. In the absence of such measures, both the adequacy of care and the concept of ageing in place—

crucial for the well-being and quality of life of older individuals—may be severely undermined (Lethin et al., 2016). Furthermore, these social developments underline the necessity for potential supplements or alternatives to family sources of informal care. Emerging evidence indicates considerable potential for non-kin informal care provided by friends or members of the older adult's neighbourhood. For instance, using SHARE data, Seifert & König (2019) estimated the prevalence of receiving neighbourhood help among the population aged 50 or older in 17 European countries at 4%. Among the countries included in our analysis, this figure ranged from 1% in Greece to 5% in Germany. Furthermore, Kalwij et al. (2014) examined the care provided by relatives (other than children), friends, and neighbours in Europe, estimating that it amounts to 30% of the hours of informal care. Fortunately, widespread claims concerning recent decreases in European neighbourhood social cohesion remain unsubstantiated. In fact, a report by Eurofound (2018) concluded that social cohesion in the EU as a whole does not seem to be at risk and that citizens generally feel strongly attached to people living in their immediate environment. This conclusion underlines the vital role that non-kin informal care can play in contemporary and future LTC systems. Despite its potential, non-kin informal care is understudied, and there remains a knowledge gap in understanding the preferences of older adults and their non-kin caregivers, as well as how such support compares to the traditional care provided by family members (Y. Zhang, 2023).

Our projections did not account for migration; nevertheless, migration—including both intra-European mobility and immigration from outside the region—is expected to exert a significant influence on Europe's demographic and caregiving landscape (Zanfrini, 2021). Increased migration could partially offset population ageing by introducing younger cohorts into the European workforce, thereby alleviating pressures on informal caregivers through an expanded labour supply in formal care sectors and enhanced support networks (Parliamentary Assembly of the Council of Europe, 2025). Migrant care workers are currently employed across

all public and private settings, from institutional to home-based care (Kumar et al., 2025). For instance, in 2019, 7.9% of the EU's long-term care workforce comprised foreign workers, with approximately 57% originating outside the EU (Eurofound, 2020). These figures—though likely underestimated since they exclude many undocumented workers—illustrate the crucial role of migrant care workers in mitigating LTC demands, including informal care, as well as their potential to help accommodate the projected increase in care demands in the future.

Nevertheless, several challenges must be addressed to fully harness the contributions of migrant workers to Europe's future care infrastructure. The EU currently lacks a sector-specific labour migration framework for attracting foreign healthcare and LTC professionals. Recognition of foreign qualifications remains complex, and recruitment processes often rely on informal or undocumented arrangements (Grubanov-Boskovic et al., 2021). Moreover, linguistic and cultural integration pose significant barriers. A heavy dependence on migrant labour also raises ethical concerns, particularly regarding the "brain drain" effect, which depletes the caregiving workforce in source countries (Jensen et al., 2024).

Advancements in artificial intelligence (AI) and robotics present a major opportunity to transform informal care in the coming decades (EUROCARERS, 2024; Sawik et al., 2023). AI-powered tools and robotic systems can support informal caregivers by enhancing efficiency, automating labour-intensive tasks, and providing caregiving knowledge. Additionally, these technologies may indirectly benefit caregivers by fostering patient autonomy and self-reliance while reducing loneliness and social isolation among care recipients (Borna et al., 2024).

While emerging evidence underscores the potential of AI-driven and robotic solutions in easing caregiving demands, realising these benefits will require policies and investments that support technology integration while addressing key deployment challenges (Wong et al., 2024). Barriers to adoption include gaps in technological literacy, perceptions of complexity,

and scepticism regarding their usefulness, alongside privacy and ethical concerns (Borna et al., 2024; Wong et al., 2024). Quality issues also persist due to potential biases and inaccuracies arising from limited or non-representative training datasets. Moreover, caregivers will require sufficient training to use these technologies effectively (EUROCARERS, 2024). The economic sustainability of these innovations also remains uncertain, as high costs and unclear funding models raise concerns about financial viability at scale (Deusdad, 2024; Wong et al., 2024). The EU and national governments have begun investing in research and pilot programs—often supported by Horizon Europe and other funding mechanisms—but ensuring these technologies are accessible, affordable, and effectively integrated into LTC will remain an ongoing challenge (Deusdad, 2024; Jensen et al., 2024).

Informal care is, and will remain, a cornerstone of LTC systems. Its importance is expected to grow as the demand for care increases across Europe, with a rising proportion of care recipients being older and more dependent. Compounding these challenges is a transforming social and economic landscape, marked by shrinking household caregiving resources and widening geographical distances between those in need of care and their families. These developments underscore the urgent need to prioritise strategic investments in prevention programmes, healthy ageing, and education. Unlocking alternative sources of informal care outside traditional family networks offers a promising pathway to mitigating the challenges of growing demand. At the same time, strengthening and expanding caregiver support is indispensable for fostering the sustainability of informal care. Without these essential informal care resources, formal long-term care systems—already stretched by financial and staffing pressures—will be unable to meet the care needs of the future.

Appendices

5.A. Data

This chapter uses data from SHARE Waves 1, 2, 3, 4, 5, 6, 7, 8 (DOIs: 10.6103/SHARE.w1.800, 10.6103/SHARE.w2.800, 10.6103/SHARE.w3.800, 10.6103/SHARE.w4.800, 10.6103/SHARE.w5.800, 10.6103/SHARE.w6.800, 10.6103/SHARE.w7.800, 10.6103/SHARE.w8.800, 10.6103/SHARE.w8ca.800, 10.6103/SHARE.w8caintd.800, 10.6103/SHARE.w9ca.800, 10.6103/SHARE.w9caintd.800) see Börsch-Supan et al. (2013) for methodological details. (1) The SHARE data collection has been funded by the European Commission, DG RTD through FP5 (QLK6-CT-2001-00360), FP6 (SHARE-I3: RII-CT-2006-062193, COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812), FP7 (SHARE-PREP: GA N°211909, SHARE-LEAP: GA N°227822, SHARE M4: GA N°261982, DASISH: GA N°283646) and Horizon 2020 (SHARE-DEV3: GA N°676536, SHARE-COHESION: GA N°870628, SERISS: GA N°654221, SSHOC: GA N°823782, SHARE-COVID19: GA N°101015924) and by DG Employment, Social Affairs & Inclusion through VS 2015/0195, VS 2016/0135, VS 2018/0285, VS 2019/0332, VS 2020/0313 and SHARE-EUCOV: GA N°101052589 and EUCOVII: GA N°101102412. Additional funding from the German Ministry of Education and Research, the Max Planck Society for the Advancement of Science, the U.S. National Institute on Aging (U01_AG09740-13S2, P01_AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, IAG_BSR06-11, OGHA_04-064, BSR12-04, R01_AG052527-02, HHSN271201300071C, RAG052527A) and from various national funding sources is gratefully acknowledged (see www.share-eric.eu).

Chapter 6

Conclusion

6. Conclusion

Europe is experiencing a significant demographic shift toward an ageing population, driven by increasing life expectancy and declining fertility rates. This transformation is prompting reforms in LTC policies across the continent, with an increasing focus on reducing institutional care and expanding reliance on informal caregiving. This paradigm shift aims to alleviate the burgeoning care demands and financial pressures on LTC systems, positioning informal care as the cornerstone of these frameworks. However, this growing dependence on informal caregivers generates considerable externalities with far-reaching societal consequences. Moreover, demographic uncertainties persist concerning the future demand for informal care resources. Ensuring the long-term sustainability of these care structures requires a multifaceted approach, incorporating data generation, analysis of the complex challenges confronting caregivers and their societal impact, as well as reliable projections of the resources needed to meet the escalating demand for informal care in the years to come. With this in mind, this thesis brings together four studies, each integrating distinct data sources and methodological approaches to address elements essential for ensuring sustained informal care.

Chapter 2 introduces the ENTWINE iCohort Study, one of the most comprehensive multinational cohort studies on informal caregiving. Recognising the intricate nature of the caregiving experience and the critical need for detailed data, this ambitious study sought to unravel the multitude of factors that converge to shape the lives of informal caregivers. The cohort comprises 1,872 caregivers and 402 care recipients from nine countries: Germany, Greece, Ireland, Israel, Italy, the Netherlands, Poland, Sweden, and the UK. Through its innovative longitudinal design, which integrates a two-wave panel survey with weekly diary

assessments, the study presents a rare opportunity to untangle the complexities of caregiving and capture its fluid and evolving dynamics. It has contributed significantly to various interdisciplinary projects, including the present work, all striving to deepen our understanding of the informal care landscape. By detailing the study's design, recruitment strategies, and data collection procedures, this chapter not only serves as a foundation for research in the field but also aspires to inspire the proliferation of similarly essential studies.

Chapter 3 investigates the associations of informal caregiving with caregivers' HRQoL and labour market participation in eight European countries: Germany, Greece, Ireland, Italy, the Netherlands, Poland, Sweden, and the UK. The results indicate that informal caregiving is associated with significant reductions in HRQoL, with impacts comparable to or exceeding those observed in certain chronic conditions. Variations in HRQoL deterioration are evident across countries and appear to be linked to individual and contextual characteristics. Caregiving intensity emerges as a key determinant of HRQoL while differentiating subgroups with heterogeneous responses to other factors. Notably, 'sandwich caregivers'—burdened by the dual responsibilities of raising children and supporting older relatives— exhibit significantly lower HRQoL. Employment shows a significant association with better HRQoL, even for part-time workers. Primary caregiving is significantly associated with poorer HRQoL among caregivers providing low levels of care. In contrast, the negative association between co-residence and HRQoL is observed only among those providing moderate levels of care.

The findings regarding support services prevalent in Europe are mixed. Financial support does not appear to correlate with improvements in caregivers' HRQoL, while respite care seems to be associated with benefits primarily in high-intensity settings. In-kind support services, including training, counselling, and information, appear to be linked to inadvertently increased stress and disrupted routines among low-intensity caregivers. This is particularly disheartening given the positive effects associated with higher perceived caregiving ability.

Cross-country differences are evident, with particularly low HRQoL observed in Italy, while in Poland and Sweden, HRQoL impairments seem to be shaped by health aspects not typically captured by the EQ-5D descriptive system.

Additionally, labour market analysis reveals a significant association between informal caregiving and reductions in work hours and at-work productivity. This negative association is disproportionately observed among women, who appear to be more likely to reduce their paid employment in favour of caregiving responsibilities. Increased caregiving intensity is correlated with reduced work hours and at-work productivity. Contrary to expectations, the receipt of caregiver support services does not appear to be associated with improved work-related outcomes.

Through a detailed case study of the Netherlands, Chapter 4 demonstrates the application of state-of-the-art methods to estimate the diverse costs of informal care. Specifically, the chapter employs opportunity cost, proxy good, and contingent valuation approaches for valuing informal caregiving time, as well as human capital and friction cost approaches for estimating indirect (productivity) costs. The chapter also illustrates the utility of these estimates in informing actionable policy recommendations.

Utilising nationally representative data, the study estimates the economic costs of informal care in the Netherlands for 2019 at €17.5 billion to €30.1 billion. These costs account for approximately 2.15% to 3.71% of the Dutch GDP, a figure nearly equivalent to public spending on LTC (2.67% of GDP). The hours of care provided by Dutch caregivers in 2019 are estimated at approximately 1.55 billion hours, equivalent to 842,416 full-time working years. The value of these hours constitutes the primary contributor to informal care costs, with women shouldering around 58% of these expenses.

Productivity costs emerge as the second major contributor to the total costs of informal care, with temporary or prolonged workforce withdrawals accounting for over 90% of these costs. While gender disparities in caregiving exist in the Dutch context, they appear relatively marginal compared to those in other parts of Europe. In light of the estimated costs, the chapter provides policy recommendations aimed at enabling caregivers to retain their jobs for as long as possible.

Chapter 5 employs a novel integration of survival analysis techniques and panel data within a microsimulation framework to project future demands for informal care over the next five decades across six European countries: Germany, Greece, Italy, the Netherlands, Poland, and Sweden. Utilising data from the SHARE survey, the chapter projects a universal increase in the demand for informal care in all examined countries, albeit with notable disparities.

Germany, Greece, and Italy are projected to experience peak demand in the 2050s and 2060s, followed by a significant decline toward the end of the projection period. In contrast, Poland and Sweden are expected to see a continuous upward trend in demand throughout the projection period. The Netherlands is anticipated to witness a steep increase in demand until the early 2050s, after which a period of moderate growth is expected. The prevalence of informal care among the population aged 50 and above is projected to rise in all countries, although to varying degrees. The analysis also indicates an increasing trend in care directed toward older recipients with dependency.

6.1. Recommendations for Future Research and Policy

According to the World Health Organisation, the primary objective of LTC systems is ‘to ensure that an individual who is not fully capable of long-term self-care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment, and human dignity’. Achieving this goal, however, should

not come at the expense of the health and financial well-being of caregivers, who contribute most significantly to it.

This concern is highlighted by our findings, which suggest substantial declines in caregiver HRQoL across all countries examined. These declines are potentially irreversible and challenging to compensate for financially. Furthermore, while the evidence linking informal care and increased healthcare utilisation remains limited, it is reasonable to assert that the accumulation of these HRQoL declines over time is likely to exert significant pressure on the caregivers and the healthcare systems that will ultimately address these burdens. With the stakes so high, there is an immediate need for targeted interventions and support systems.

Compounding these health declines are the profound economic consequences associated with informal care. Our estimates unveil staggering market productivity losses in the Netherlands, ranging from 45.1 million to 210.3 million hours of foregone paid labour. These figures, striking for a nation renowned for its generous LTC system, portend even greater proportional losses in countries with less developed LTC systems and heavier reliance on informal care.

This economic toll serves as a clarion call for labour market policies to address the employment challenges faced by caregivers and support their continued workforce participation. Furthermore, with women disproportionately shouldering caregiving duties and experiencing employment repercussions, they must be at the forefront of these policies. Adding to its economic significance, employment can also confer health benefits for caregivers, reinforcing the case for policy intervention to address their employment challenges. The thesis demonstrates the feasibility of reliably estimating informal care costs and their potential to enrich policy discourse. The onus now falls on policymakers to incorporate these hitherto overlooked costs into their decision-making processes.

Another key area where incorporating informal care costs would have particularly significant implications is the economic evaluation of technological innovations aimed at reducing caregiving burdens. Conventional cost-effectiveness analyses often overlook informal care costs, implicitly treating caregiving as a cost-free societal resource despite the considerable time and effort it entails. As a result, innovations designed to alleviate caregiving demands may struggle to demonstrate economic viability compared to the ostensibly 'costless' alternative of informal care. This systemic undervaluation creates a structural disincentive for investing in care-related technologies. One potential avenue for addressing this issue involves recalibrating economic assessments to explicitly quantify and incorporate the 'hidden' costs of informal care, thereby enabling such innovations to demonstrate their true value. Additionally, targeted subsidies or grants could be introduced to foster an environment conducive to the development and adoption of such technologies. Greater alignment between health and social care financing mechanisms may also be necessary to ensure that such innovations receive adequate economic recognition and funding. Without these adjustments, the prevailing status quo risks stifling the development and adoption of transformative innovations capable of enhancing the sustainability of LTC systems.

The caregiving experience is characterised by inherent heterogeneity, influenced by a multitude of intertwining factors that shape each caregiver's journey. Our findings affirm this complexity, illuminating critical areas for policy intervention. This thesis advocates for abandoning the one-size-fits-all approach to service design, which is often ineffective and particularly ill-suited for addressing the diverse needs of caregivers. For instance, while our study suggests that the perceived ability to care may be associated with improved caregiver HRQoL, training and information services meant to enhance this ability may be ineffective for some and burdensome for others. Likewise, financial support appears to have no association

with either health or labour market outcomes. Regarding respite care, the recommendation is to prioritise caregivers providing intensive care whenever possible.

Importantly, these concerns should not be seen as a call to eliminate support services altogether. Instead, they underscore the need to rethink the entire suite of caregiver support packages to better align with the distinct needs of various user groups. This thesis also calls on scholars to address the critical gap in evidence regarding the (cost-)effectiveness of caregiver support services, particularly financial support. Future studies should be rigorously designed, ideally employing randomised control trials, utilising sufficiently large sample sizes, collecting comprehensive dyadic data, and incorporating cost information to facilitate economic evaluations.

Throughout this thesis, I came to realise the potential of further studies addressing informal caregiving. In particular, longitudinal studies would be valuable in capturing the temporal changes in caregiving demands and outcomes, offering a deeper understanding of causal relationships that cross-sectional studies cannot provide. While the ENTWINE iCohort Study introduced in this thesis represents a welcome addition to the field, its short 6-month follow-up period limits the ability to explore long-term patterns and outcomes. The Informal Care Study used in this thesis provides a representative sample of the Dutch population and specifically targets informal caregivers. Nevertheless, it is limited to three waves of cross-sectional data rather than a longitudinal design, which restricts the ability to observe changes over time. SHARE is probably the most widely used longitudinal dataset in European informal care research, contributing significantly to our understanding of caregiving across the continent. However, since SHARE was not designed specifically to investigate informal care, it lacks essential details, such as caregiving intensity (after wave 2), which limits detailed analyses of the phenomenon. Establishing and maintaining a longitudinal study that addresses all these needs would be costly, time-consuming, resource-intensive, and requiring coordinated

interdisciplinary efforts. However, considering the challenges identified in this work and the broader literature, such an endeavour would be an invaluable contribution to the field.

Furthermore, this thesis anticipates a heightened role for informal care within Europe's future LTC landscape. This trend is expected to prevail even if the current per capita public expenditure on LTC remains unchanged—a scenario that seems overly optimistic considering historical policy shifts. The demand for informal care is projected to exhibit significant regional variability across the continent, with peaks in demand manifesting asynchronously. Such projections are indispensable for European policymakers, enabling them to plan effectively in anticipation of these intense demands. Equally significant is the projected increase in the intensity of care, particularly in light of the anticipated shrinking pool of potential caregivers. This diminishing pool is likely to face the challenge of supporting a demographic of care recipients that is not only growing as a proportion of the total population but also ageing and exhibiting higher dependency levels than those currently observed.

With these demographic patterns not easily reversed, European policymakers must enact immediate measures to facilitate healthy ageing. These measures should focus on implementing preventive strategies to avert health issues and enhance well-being; ensuring accessible, high-quality care that evolves with the population's needs; promoting age-friendly communities; and supporting the generation of relevant data to guide these initiatives. Efforts should also focus on strengthening the role of migrant care workers through policies that facilitate their integration, streamline qualification recognition, and ensure fair labour conditions, while also making the sector more attractive to the domestic workforce. At the same time, investments in technological innovations for caregiver support, including AI and robotics, should be prioritised to enhance their effectiveness, affordability, and integration into LTC.

Collectively, this thesis unravels how the sustainability of LTC systems in an ageing Europe hinges on a complex interplay of factors. No singular solution can independently fully address the multifaceted challenges posed by population ageing. The prevailing trend of shifting care responsibilities onto informal caregivers is no exception, particularly when the profound burdens they endure are considered. These burdens manifest as substantial health and productivity losses that reverberate across society. When these losses are viewed against the backdrop of the projected increase in demand for informal care, the gravity of the sustainability challenges becomes unmistakably evident. These challenges are further exacerbated by the anticipated decline in the working-age population, a demographic increasingly relied upon to provide care, thereby curtailing their labour force engagement. This scenario casts further doubts on the long-term viability of current LTC policies.

Tackling these challenges necessitates a comprehensive policy approach that addresses caregivers' health outcomes and the broader economic repercussions of informal care. This thesis pinpoints several key areas for intervention: revamping caregiver support services to be evidence-based and responsive to caregivers' diverse needs; developing training programs that empower caregivers with essential skills to navigate their responsibilities effectively; and devising labour market policies that enable caregivers to balance professional commitments with caregiving duties.

Moreover, investing in education presents a dual-benefit strategy that not only enhances health outcomes and reduces dependency levels among care recipients but also improves the socioeconomic prospects of caregivers. A commitment to 'healthy ageing' initiatives is also imperative, ensuring the well-being of the ageing population and fostering a more autonomous and healthier ageing trajectory. Lastly, policy measures must proactively adapt to the dynamic demand for informal care, aligning with the evolving demographics of caregivers and care recipients. Only through such comprehensive and adaptive measures can we forge a sustainable

path for Europe's LTC systems, ensuring they are robust and resilient enough to withstand the challenges of time and demographic shifts.

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Samenvatting

Europa ondergaat een ingrijpende demografische verschuiving naar een vergrijzende bevolking, gedreven door een hogere levensverwachting en een dalend geboortecijfer. Veel landen hebben beleidshervormingen doorgevoerd die institutionele zorg verminderen en mantelzorg bevorderen. Dit beleid is gericht op het verlichten van de financiële druk en het inspelen op de groeiende zorgvraag, maar legt een zware last op mantelzorgers, met gevolgen voor hun gezondheid en economische situatie. De toekomstige vraag naar mantelzorg blijft hoog en zal naar verwachting toenemen, wat vragen oproept over de lange termijn houdbaarheid van Europese langdurige zorgstelsels.

Deze dissertatie stelt dat de houdbaarheid van langdurige zorg verder reikt dan financiële stabiliteit en ook de bredere externe effecten omvat die andere belanghebbenden dan de zorgontvangers ervaren. In het bijzonder maken mantelzorgers aanzienlijke persoonlijke offers en dragen zij tijd en middelen bij met een geschatte economische waarde van miljarden euro's, dat wil zeggen van dezelfde orde grootte als formele langdurige zorg. Een duurzamer langdurig zorgsysteem vereist uitgebreide gegevens over mantelzorg, een grondige analyse van de gevolgen voor gezondheid en werkgelegenheid, en robuuste schattingen van de maatschappelijke kosten van mantelzorg. Daarnaast zijn betrouwbare projecties van de toekomstige vraag naar mantelzorg essentieel voor goed onderbouwd beleid.

Deze dissertatie richt zich op de Europese context en maakt gebruik van uiteenlopende gegevensbronnen en methoden om de bredere gevolgen van mantelzorg te onderzoeken. Hierbij wordt gekeken naar de impact op de gezondheid, tijdsbesteding en arbeidsparticipatie van mantelzorgers, de bredere implicaties van mantelzorg en de toekomstige vraag naar mantelzorg.

De dissertatie bestaat uit vier zelfstandige studies, die elk een specifiek aspect van mantelzorg belichten met behulp van onderscheidende methoden.

Hoofdstuk 2 introduceert de ENTWINE iCohort Study, een van de meest uitgebreide multinationale cohortstudies over mantelzorg. Erkennend dat mantelzorg een complex fenomeen is en dat gedetailleerde gegevens essentieel zijn, had deze studie tot doel de vele factoren te ontrafelen die het leven van mantelzorgers beïnvloeden. De cohortstudie omvat 1.872 mantelzorgers en 402 zorgontvangers uit negen landen: Duitsland, Griekenland, Ierland, Israël, Italië, Nederland, Polen, Zweden en het Verenigd Koninkrijk. Dankzij de longitudinale opzet, waarin twee enquêtemetingen worden gecombineerd met wekelijkse dagboekmetingen, biedt de studie unieke inzichten in de dynamiek van mantelzorg. De studie heeft bijgedragen aan diverse interdisciplinaire onderzoeksprojecten, waaronder deze dissertatie, en levert een waardevolle bijdrage aan het begrip van mantelzorg. Dit hoofdstuk beschrijft de onderzoeksopzet, wervingsstrategieën en dataverzameling en vormt de basis voor verder onderzoek op dit gebied.

Hoofdstuk 3 onderzoekt de relatie tussen mantelzorg, gezondheidsgerelateerde kwaliteit van leven (HRQoL) en arbeidsmarktdeelname in zeven Europese landen: Duitsland, Ierland, Italië, Nederland, Polen, Zweden en het Verenigd Koninkrijk. De resultaten tonen aan dat mantelzorg gepaard gaat met aanzienlijke afnames in HRQoL, waarbij de impact vergelijkbaar is met of zelfs groter dan die van bepaalde chronische aandoeningen. Er zijn aanzienlijke verschillen tussen landen, waarbij individuele en contextuele factoren een rol spelen. De intensiteit van mantelzorg blijkt een belangrijke bepalende factor. ‘Sandwichzorgverleners’—die zowel voor hun kinderen als voor oudere familieleden zorgen—rapporteren een significant lagere HRQoL. Werk is geassocieerd met een betere HRQoL, zelfs bij deeltijdwerkers.

De arbeidsmarktanalyse laat zien dat mantelzorg leidt tot een afname in gewerkte uren en productiviteit. Dit effect is vooral zichtbaar bij vrouwen, die vaker hun betaalde werkuren verminderen ten gunste van zorgtaken. Een hogere zorgintensiteit correleert met verdere afname in werkuren en productiviteit. Tegen de verwachtingen in blijkt de ontvangst van ondersteunende diensten niet geassocieerd te zijn met verbeteringen op deze gebieden.

Hoofdstuk 4 toont aan de hand van een casestudy van Nederland hoe geavanceerde methoden kunnen worden toegepast om de economische kosten van mantelzorg te ramen. Dit hoofdstuk gebruikt de opportunity cost-, proxy good- en contingent valuation-methoden om de waarde van zorgtijd te schatten en de human capital- en friction cost-methoden om indirecte (productiviteits)kosten te bepalen. Daarnaast illustreert het hoofdstuk hoe deze schattingen kunnen bijdragen aan beleidsmaatregelen die mantelzorgers beter ondersteunen bij het combineren van werk en zorgtaken.

Hoofdstuk 5 integreert overlevingstechnieken en paneldata binnen een microsimulatiekader om projecties te maken van de toekomstige vraag naar mantelzorg in zes Europese landen: Duitsland, Griekenland, Italië, Nederland, Polen en Zweden. Op basis van gegevens uit het SHARE-onderzoek worden in alle landen stijgingen in de vraag naar mantelzorg geprojecteerd, met aanzienlijke verschillen tussen landen.

Duitsland, Griekenland en Italië zullen een piek in de zorgvraag ervaren in de 2050s en 2060s, gevolgd door een scherpe daling. In Polen en Zweden wordt een voortdurende stijging verwacht. Voor Nederland wordt een sterke toename tot de vroege 2050s geprojecteerd, gevolgd door een periode van gematigde groei. De prevalentie van mantelzorg onder 50-plussers neemt in alle landen toe, zij het in verschillende mate. De analyse laat ook een stijgende trend zien in zorg voor oudere zorgontvangers met afhankelijkheid.

Gezamenlijk laat deze dissertatie zien dat de houdbaarheid van langdurige zorg in een vergrijzend Europa afhankelijk is van een complex samenspel van factoren. Geen enkele oplossing kan de veelzijdige uitdagingen van de vergrijzing volledig oplossen. De verschuiving van zorgtaken naar mantelzorgers vormt hierop geen uitzondering, zeker gezien de zware lasten die zij dragen. Deze lasten manifesteren zich als aanzienlijke gezondheids- en productiviteitsverliezen met brede maatschappelijke gevolgen. Gezien deze verliezen en de geprojecteerde stijging van de vraag naar mantelzorg wordt de urgentie van deze problematiek steeds duidelijker. Dit wordt verder versterkt door de verwachte afname van de beroepsbevolking—een groep die steeds vaker verantwoordelijk wordt voor zorgverlening, waardoor hun deelname aan de arbeidsmarkt wordt beperkt. Dit roept fundamentele vragen op over de lange termijn levensvatbaarheid van het huidige beleid voor langdurige zorg.

university of groningen

A Stepping-stone Towards Sustainable Long-term Care in Europe

Saif Elayan

Europe is experiencing a major demographic shift toward an ageing population, driven by longer life expectancy and declining fertility. This transformation has prompted policy reforms across the continent, reducing institutional care while increasing reliance on informal caregiving. While aimed at easing financial pressures and meeting rising care demands, this shift burdens informal caregivers, leading to health and economic repercussions. Meanwhile, future demand for informal care remains uncertain, raising further concerns about the long-term sustainability of European long-term care (LTC) systems.

This PhD thesis examines the externalities of informal care on caregivers' health, time, and employment, assesses their broader implications, and projects future demand for this essential care. To this end, we conducted a multinational survey on informal caregiving across eight European countries—Germany, Greece, Ireland, Italy, the Netherlands, Poland, Sweden, and the UK. Using these data, we investigated how caregiving relates to caregivers' health and labour market outcomes. We found significant associations between caregiving and poorer health, reduced work hours, and lower productivity, with variations across countries, individual characteristics, and contextual factors.

Next, using nationally representative data, we applied state-of-the-art methods to estimate the societal costs of informal care in the Netherlands in 2019. Our findings revealed substantial costs, primarily in the form of time and productivity losses, amounting to 2.15%–3.71% of Dutch GDP—comparable to public LTC spending. Finally, leveraging SHARE survey data, we projected a universal increase in informal care demand among individuals aged 50+, alongside a trend of care provision towards older recipients with greater dependency.