Care needs in home care

Predictors of nursing home transition and caregiver distress

Inga Valgerður Kristinsdóttir

Thesis for the degree of Philosophie Doctor

2025

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Umönnunarþarfir í heimaþjónustu

Þættir sem spá fyrir um flutning á hjúkrunarheimili og umönnunarbyrði aðstandenda

Inga Valgerður Kristinsdóttir

Ritgerð til doktorsgráðu

Leiðbeinandi

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Ágrip

Eldra fólki fjölgar um allan heim og stjórnvöld leggja áherslu á að gera þeim kleift að búa áfram á eigin heimili eins lengi og mögulegt er, þrátt fyrir heilsubrest og líkamlega og vitræna skerðingu. Flest eldra fólk kýs að búa áfram á heimilum sínum þrátt fyrir þörf fyrir aðstoð frá formlegri þjónustu og aðstandendum. Með því að kortleggja heilsufar, líkamlega færni og vitræna getu einstaklinga sem njóta heimaþjónustu yfir tíma, er hægt að leggja mat á umönnunarþarfir þeirra sem og stuðningsþarfir aðstandenda. Slík greining er mikilvæg við þróun og úrbætur heimaþjónustu.

Doktorsverkefni þetta byggir á gögnum úr rannsókn sem framkvæmd var í sex Evrópulöndum — Belgíu, Finnlandi, Þýskalandi, Íslandi, Ítalíu og Hollandi, á árunum 2014 til 2016. Rannsóknin, sem kallast Identifying Best Practices for Care-dependent Elderly by Benchmarking Costs and Outcomes of Community Care (IBenC), skoðaði einstaklinga 65 ára og eldri sem bjuggu sjálfstætt og nutu aðstoðar frá formlegri heimaþjónustu ásamt stuðningi frá aðstandendum. Í úrtakinu voru 2.884 eldri einstaklingar, sem metnir voru með interRAI-Home Care (HC) matstækinu á þremur tímapunktum yfir tólf mánaða tímabil.

Doktorsverkefnið inniheldur þrjár rannsóknir. Í þeirri fyrstu var kannað hvort breytingar hefðu orðið á heilsufari og færni skjólstæðinga heimaþjónustu, auk þess hvort framboð þjónustu hefði breyst á tímabilinu 2001 til 2014 í fimm Evrópulöndum. Niðurstöður tveggja rannsókna, þar sem interRAI-HC mælitækið var notað, Aged in Home Care (AdHOC) frá 2001 og IBenC frá 2014, voru bornar saman. Við samanburðinn voru notaðar krosstöflur og kí-kvaðrat próf. Niðurstöður sýndu að líkamlegri og vitrænni færni einstaklinganna hafði hnignað á milli áranna 2001 og 2014 og á sama tímabili hafði heimaþjónusta aukist, sem bendir til að stjórnvöld hafi brugðist við auknum umönnunarþörfum, eldra fólks, að einhverju marki. Þá voru gögn frá IBenC rannsókninni greind enn frekar með tilliti til þess hvort þeir sem höfðu mestar umönnunarþarfir hefðu fengið verulega aðstoð frá heimaþjónustu. Niðurstöðurnar sýndu að um helmingur þeirra sem voru í mestri þörf fyrir aðstoð fengu flestar mínútur í aðstoð, en þetta hlutfall var mjög breytilegt milli landa. Í Þýskalandi fengu nær 90% einstaklinga með mikla þörf umfangsmikla þjónustu, en á Ítalíu voru aðeins 10% þeirra í sömu stöðu sem fengu umfangsmikla aðstoð.

Í rannsókn tvö var athyglinni beint að umönnunarbyrði aðstandenda þeirra sem njóta heimaþjónustu. Lýsandi tölfræði og aðhvarfsgreiningarlíkön voru notuð til að greina þætti sem tengdust álagi á aðstandendur. Þessi þversniðsrannsókn, gerð í sex löndum, sýndi að hærra hlutfall umönnunaraðila á Íslandi upplifði umönnunarbyrði, eða 34%

þeirra, miðað við 9%–22% í hinum þátttökulöndunum. Helstu forspárþættir fyrir umönnunarbyrði voru einkenni um þunglyndi umönnunarþegans, þvagleki, nýleg sjúkrahúsinnlögn og vísbendingar um versnandi heilsufar. Þessar niðurstöður undirstrika mikilvægi þess að fylgjast með líðan aðstandenda og bregðast við þáttum er stuðla að álagi á þá.

Þriðja rannsóknin kannaði breytingar á heilsufari, líkamlegri og andlegri færni og aðstæðum einstaklinga er njóta heimaþjónustu yfir tólf mánaða tímabil. Niðurstöðurnar sýndu hnignun á heilsu og færni, metnar út frá niðurstöðum kvarða úr interRAI-HC matstækinu, s.s. kvörðum sem meta líkamlega og vitræna getu, einkenni þunglyndis og breytingar á heilsufari og sjúkdómum. Niðurstöðurnar sýndu einnig að formleg þjónusta jókst lítillega á rannsóknartímabilinu. Um 12% skjólstæðinganna í löndunum fjórum fluttu á hjúkrunarheimili á tímabilinu. Þeir sem fluttu á hjúkrunarheimili voru að meðaltali eldri og höfðu verri vitræna og líkamlega færni, en þeir sem enn bjuggu heima. Þættir sem spáðu fyrir um flutning á hjúkrunarheimili voru mismunandi á milli landanna. Á Íslandi var umönnunarbyrði aðstandenda sterkasti forspárþátturinn, á meðan líkamleg geta var lykilþáttur í Finnlandi. Í Belgíu og Þýskalandi var sterkasti forspárþátturunni að einstaklingur eða umönnunaraðili taldi að honum hentaði betur að búa annars staðar.

Niðurstöður doktorsverkefnisins varpa ljósi á vaxandi umönnunarþarfir eldra fólks og mikilvægi stuðnings aðstandenda við þá til áframhaldandi búsetu þeirra á eigin heimili. Leggja þarf áherslu á sérsniðna umönnun einstaklingsins og öflugan stuðning við aðstandendur, sem tekur mið af heilsufari og færni hvers og eins og þeim fjölbreyttu þáttum sem hafa áhrif á flutning á hjúkrunarheimili. Með því að greina einstaklingsbundnar þarfir skjólstæðinga hámarkast líkur því að opinber stuðningskerfi geti þróað markvissar íhlutanir til stuðnings áframhaldandi búsetu, eldra fólks, á eigin heimili.

Lykilorð:

Heimaþjónusta, umönnun aðstandenda, umönunarbyrði, forspárgildi, interRAI-Home Care.

Abstract

The global population is aging, and policymakers emphasize the importance of enabling older people to continue living in their private homes for as long as possible, even as they experience health decline and physical or cognitive impairment. While most older individuals prefer to live independently, many require assistance from formal care systems and family caregivers. By mapping the health, physical, and cognitive abilities of home care clients over time, their care needs as well as the needs of their caregivers for support can be identified. Such analysis facilitates the establishment of strategies for the development and improvement of home care services.

This doctoral research project draws on a study conducted in six European countries—Belgium, Finland, Germany, Iceland, Italy, and the Netherlands—between 2014 and 2016. The study—named as Identifying Best Practices for Care-dependent Elderly by Benchmarking Costs and Outcomes of Community Care (IBenC)—focused on individuals aged 65 years and older who lived independently and received assistance from formal home care services as well as support from family caregivers. The sample included 2,884 older home care clients, who were assessed using the comprehensive interRAI-Home Care (HC) assessment tool, at three timepoints during twelve-months follow-up.

The project included three studies. The first study examined the changes in health and functional profile of home care clients and the services provided between 2001 and 2014 in five European countries. The study compared the findings of two studies using the same data collection method, the Aged in Home Care (AdHOC) study from 2001 and the IBenC study from 2014. Results revealed a significant decline in home care clients' physical and cognitive abilities between 2001 and 2014, with an increase in formal care services provided during the same period. Cross-tabulations and chi-square tests were used for the comparison. These findings suggest that government policies aiming at enabling older people to remain at home, even with advanced impairment, have been partially realized. Moreover, data from the IBenC study were analysed to examine the distribution of home care services, specifically to investigate whether individuals with the highest care needs received substantial assistance from the formal care system. The findings revealed that, approximately half of home care clients with the highest care needs received the most minutes of assistance. However, this distribution varied significantly between countries. In Germany, nearly 90% of home care clients with severe care needs received the highest level of assistance, whereas in Italy, only 10% of home care clients in similar situatioin received substantial home care.

The second study focused on caregiver distress among home care caregivers, as more older people rely on family or informal caregivers for support to continue to live at home. Descriptive statistics and logistic regression models were used to identify predictive variables for caregiver distress. This cross-sectional study across six countries revealed that caregiver distress was markedly higher in Iceland (34%) than in other countries (9%–22%). Key predictors of caregiver distress included the care recipient's depression, bladder incontinence, recent hospitalizations, risk of significant health decline or those with increased care needs. These findings emphasize the importance of monitoring caregiver well-being and addressing factors that contribute to their burden.

The third study examined the changes in health, physical and cognitive abilities, and circumstances among home care clients over a 12 month period. The results showed a general decline in health and abilities, as measured by the outcome scales from the interRAI-HC assessment tool, e.g. cognitive scale, a scale that assess activities of daily living, a scale that measures symptoms of depression and another assesses changes in health status and diseases. Additionally, the findings revealed that the formal care increased slightly over the one year study period. The results from four of the participating countries also showed that 12% of clients moved to nursing homes over the study period. Home care clients who moved to nursing homes were, on average, older and showed more significant declines in health and overall ability, than those still living at home. An investigation of the predictors of transition to nursing homes among home care clients showed that the factors influencing this transition varied significantly by country. In Iceland, caregiver distress emerged as the strongest predictor, whereas in Finland, physical ability was the primary determinant. In Belgium and Germany, the strongest predictor was the client's or caregiver's belief that the older individual would be better off living elsewhere.

The findings of this thesis highlight the increasing complexity of home care services and the critical role of caregivers in supporting older people to age in place. The findings underscore the need for tailored care strategies that address the care recipient's health and functional needs, alleviate caregiver distress, and consider the diverse predictors of nursing home transition across countries. By understanding these challenges, healthcare systems can develop targeted interventions to effectively enhance home care services and support aging populations.

Keywords:

Home care, caregiver, caregiver distress, predictors, interRAI-Home Care.

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Taking on this PhD journey would not have been possible without the support, guidance, and encouragement of those around me. I am incredibly fortunate to have had such people by my side and am forever grateful to each of them for accompanying me on this path and supporting me every step of the way.

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Thank you all for standing by my side during this incredible doctoral adventure—I love you all.

Contents

List of Abbreviations

AdHOC	AgeD in the Home Care
ADL	Activities of Daily Living
ADLH	Activities of Daily Living Hierarchy scale
ANCIEN project	Assessing Needs for Care in European Nations
ANOVA	Analysis of Variance
CAPs	Client assessment protocols
CG	Caregiver
CHESS Scale	Changes in Health, End-Stage Disease and Signs and Symptoms
CI	confidence interval
CPS	Cognitive Performance Scale
DRS	Depression Rating Scale
IBenC	Identifying Best Practices for Care-Dependent Elderly by Benchmarking Costs and Outcomes of Community Care
interRAI-HC	interResident Assessment Instrument for home care
LTC	Long Term Care
MAPLe	Method for Assigning Priority Levels algorithm
MDS	Minimum data set
NDC	Non-distressed caregiver
OECD	The Organisation for Economic Cooperation and Development
OR	Odds ratio
RUGs	Resource utilization groups
SD	Standard deviation
UN	United Nations
WDC	With a distressed caregiver
WHO	World Health Organization

Clarification

The terms 'Home care clients' and 'older people receiving home care ' are used interchangeably throughout the thesis.

List of Figures

List of Tables

List of Original Papers

This thesis is based on the following original papers, which are referred to in the text by their Roman numerals (I, II, and III):

I. Kristinsdottir, I.V., Jonsson, P.V., Hjaltadottir, I.,& Bjornsdottir, K. (2021). Changes in home care clients´ characteristics and home care in five European countries from 2001 to 2014: comparison based on InterRAI-Home Care data. *BMC Health Services Research, 21,* 1177. https://doi.org/10.1186/s12913-021-07197-3

II. Kristinsdottir, I.V., Jonsson, P.V., Hjaltadottir, I. & Bjornsdottir, K. (2025). Prevalence and predictors of caregiver distress in six European communities: Data from the IBenC study, using interRAI-Home care assessments. *Scandinavian Journal of Caring Sciences*, *39*(1), e70005. https://doi.org/10.1111/scs.70005

III. Kristinsdottir, I.V., Hjaltadottir, I., Jonsson, P.V., Gudnadottir, S.A. and Bjornsdottir, K. (2025). Characteristics of home care clients as predictors for admission to nursing homes: analysis based on interRAI-Home Care data from four European Communities. (Submitted to be published)

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Declaration of Contribution

The doctoral candidate, Inga Valgerður Kristinsdóttir (IVK), wrote this doctoral thesis under the guidance of her supervisor, Kristín Björnsdóttir, and the other members of the doctoral committee: Pálmi V. Jónsson, Ingibjörg Hjaltadóttir, and Thor Aspelund.

This thesis is based on data from the European IBenC study (Identifying Best practices for care-dependent elderly by Benchmarking Costs and outcomes of Community Care), which was funded by the Seventh Framework Programme of the European Union. IVK served as the research coordinator for the IBenC study in Iceland, where she was responsible for obtaining all necessary permissions, organizing the data collection process, and actively participating in the data collection herself.

IVK designed the studies in collaboration with all of the doctoral committee. IVK analysed the data with supervision of Thor Aspelund and in Study III IVK and Sigurbjörg Anna Guðnadóttir analysed those the data. IVK drafted the manuscripts, and all authors critically revised them, interpreted the results and ultimately approved the manuscripts.

1 Introduction

The idea for this dissertation developed from my experience in home care. I have worked in home nursing for nearly my entire career, first as a team leader, then as department manager, and finally as a specialist in home care nursing or an advanced practice nurse (APN). In my work, I have often reflected on the direction that home care services could take to better meet the needs of clients, especially older people. A growing body of research findings from many countries indicates that older people with complex health problems continue to live in their own homes longer than in Iceland. Studies indicate that older people who receive home care services in Iceland generally have better physical and cognitive abilities than their counterparts in countries we compare ourselves to. This prompted my interest in knowing how home care services could be improved to support them in living longer at home despite declining overall ability and health.

Owing to my work as a home care nurse, I have interacted with many older people and their family caregivers. The older people are often worried about becoming a burden on their loved ones, whereas their family members are often uncertain about what services the older person is entitled to from the public system or what is expected of them as caregivers. In 2014, I assumed the role of a project manager for a study funded by the European Union conducted simultaneously in six European countries: Belgium, Finland, Germany, Italy, the Netherlands, and Iceland. The study aimed to assess the health, physical and cognitive abilities, and circumstances of older people receiving home care in the respective countries using the comprehensive assessment tool interRAI–Home Care (HC). The results can be used to identify areas of concern and potential opportunities to enhance home care services in each country and provide an opportunity to compare findings between participating countries. Based on these results home care services for older individuals living at home could be improved, extending their stay at the place they most often prefer—their home.

2 Background

2.1 Older people living at home

The global population is aging, with a significant increase in the proportion of older people. In Europe, the percentage of individuals aged 65 years and older is expected to rise from 16% in 2010 to approximately 30% by 2060 (Organization of Economic Cooperation and Development [OECD], 2023). This demographic shift presents both challenges and opportunities for health and social care systems. Policymakers and international organizations, including the World Health Organization (WHO) and the United Nations (UN), have emphasized the concept of 'aging in place', advocating for older people to remain in their own homes rather than transitioning to nursing homes. Consistent with this vision, the UN has declared the period 2021–2030 as the decade of healthy aging (WHO, 2020), promoting the importance of enabling older individuals to age in their homes with adequate care and support systems. Governments worldwide have encouraged independence among older populations, leading to an increasing number of older people with care needs who continue to live at home, supported by formal and informal caregivers (Cesari et al., 2016; Genet et al., 2013; Pickard, 2011).

Most older people prefer to remain living independently in their homes (Ratnayake et al., 2022), where they can maintain their social connections, quality of life, and a sense of comfort in a familiar environment (Wiles et al., 2012). This approach of aging in place offers numerous benefits, including greater control over their daily lives, enhanced independence, and increased autonomy. Furthermore, older individuals often have established social roles and relationships within their communities or neighbourhoods, which significantly contribute to their overall well-being (Martin et al., 2019).

Supporting aging in place may call for provision of comprehensive assistance, including specialized services for complex care needs. However, despite this clear policy, many healthcare systems face challenges in effectively implementing this approach owing to insufficient funding and poor coordination between social and healthcare services, resulting in unmet needs among home care clients. This doctoral study aimed to provide insights into this situation by exploring the needs of older people who receive home care services and their caregivers to identify how home care services may be developed to better respond to these needs and support to live at home longer.

2.2 Home care

The growing aging population underscores the importance of home care services. These services must be flexible and proactive, adapting to changing needs, integrating care across providers, and addressing limitations in availability (Barber et al., 2022). Older people often face declining physical and cognitive functions, which make daily tasks challenging. Home care enables them to remain in familiar environments, preserving their independence and psychological well-being, as familiar routines provide comfort and a sense of security. In many countries, home care services have become a critical component of community services developed to support individuals to continue living at home. The scope of home care is broad and heterogeneous, which often leads to ambiguity in its definition. However, Bjornsdottir (2008, p. 53) defined home care as 'health services delivered to individuals and families in their homes, aiming to assist with daily activities, alleviate suffering, prevent health issues, and promote overall well-being'. Home care refers to formal care provided by professional caregivers within a home environment, designed to complement—and in some cases, replace—hospital care over an extended period, thereby enabling individuals to remain in their homes longer (Genet et al., 2012; Thomé et al., 2003). Home care nurses play a central role in these services, overseeing the management of long-term health conditions, working to prevent hospital admissions, and providing clinical leadership (Fjørtoft et al., 2021: Martinsen et al., 2018).

Community-based home care services are essential in supporting older people to maintain their independence and enhance their well-being. These services include assistance with daily activities and management of chronic conditions, tailored to individual needs, and provided in collaboration with family caregivers and formal care systems (Bjornsdottir et al., 2021). Such services involve close collaboration with the person needing care, family caregivers, and the formal care system. The policy goal of enabling older people to live at home for as long as possible has placed family members at the forefront of caregiving, making them integral to the care chain (Bjornsdottir, 2017). This highlights the necessity of home care services to support not only care recipients but also family caregivers, ensuring the sustainability of home-based care.

With increased survival rates among individuals with chronic illnesses and multimorbidity, care demands are expected to rise, leading to an increased demand for nursing home placements. This has led to interest in exploring whether home care services can be further developed to meet the needs of both clients and caregivers. By tailoring home care to the specific needs of individuals and providing appropriate support to caregivers, home care services can play a significant role in delaying the transitions to institutional care. This doctoral research project aimed to contribute to knowledge regarding how older people can be enabled to remain in their homes, thereby improving their quality of life while alleviating pressure on institutional care systems.

2.2.1 Overview of home care systems in participating countries

In the context of this study, home care services were examined across six European countries participating in the IBenC project: Belgium, Finland, Germany, Iceland, Italy, and the Netherlands. While the organization and provision of home care vary across countries, they share a common focus on supporting older people through a combination of health and social care services directed by professionals, clients´ self-care and informal care provided by family caregivers.

In Belgium, nursing care is a federal responsibility and is largely financed through public health insurance, whereas domestic and family care services fall under regional authority and are primarily funded through community taxation (Genet et al., 2012). The care system in Germany is built on a mandatory long-term care insurance scheme, which allows individuals to choose between receiving in-kind services or cash benefits for informal caregiving. Services are assigned based on five care levels and include support such as personal care, home nursing, respite services, and caregiver compensation. Individuals with higher economic status more often use the cash benefits to hire professional caregivers, while others may rely on family care supported by allowances (Genet et al., 2012). The Netherlands also has a well-established long-term care insurance system, but local municipalities play a stronger role in coordinating care. Nursing care is federally organized, while social and domestic services are managed locally. A notable feature of the Dutch model is the emphasis on integrated care to provide coordinated and client-centered home care (Genet et al., 2012). Italy has a fragmented home care system with significant regional variation. While basic care is publicly funded, families often use personal allowances—such as the companion benefit—to hire informal or migrant caregivers, leading to inconsistent access to professional home care (Genet et al., 2012). In Iceland, home health care is delivered by regional home care centers operated by the national government, except in Reykjavik, the capital, where home care nursing has been integrated with the social services (but still funded by the state). These services include nursing care and assistance with ADLs. Social support services—such as personal assistance, meal delivery, and household help—are provided by local municipalities. Together, they form the structure for open geriatric services outlined in national legislation (Genet et al., 2012; Van Eenoo et al., 2016). In Finland, home care is the responsibility of municipalities and is funded through local taxation. Services typically include nursing care, support with daily living, and domestic help, and the system increasingly involves informal caregivers, who may receive care allowances or service vouchers (Genet et al., 2012).

Together, these systems illustrate the variety of organizational models, funding mechanisms, and delivery approaches present in Europe. This diversity provides an important contextual foundation for understanding how care is structured and accessed across different countries, particularly in relation to older adults with complex needs and the family caregivers who support them.

All six countries participating in the IBenC study are member states of the World Health Organization (WHO) where the policy of aging in place has been developed. Iceland, Finland, Belgium, Germany, and the Netherlands have adopted national or regional strategies that reflect this goal—through integrated care, community-based services, and decentralized provision Italy's approach is more fragmented, with less emphasis on formal support for aging in place and greater reliance on informal care (Genet et al., 2012; Van Eenoo et al., 2016).

2.2.2 The IBenC study

This doctoral thesis is based on three interrelated studies utilizing data from the research project titled Identifying Best Practices for Care-Dependent Elderly by Benchmarking Costs and Outcomes of Community Care (IBenC), conducted between 2014 and 2016. Its primary goal was to identify and characterize best practices in home care delivery for care-dependent older adults by benchmarking the cost-effectiveness of various community care models across six European countries: Belgium, Finland, Germany, Iceland, Italy, and the Netherlands (Van de Roest et al., 2019). The project collected longitudinal data on 2,884 home care clients aged 65 and over, as well as information from 1,067 care professionals across 38 home care organizations. Using the interRAI Home Care (interRAI-HC) assessment, the study evaluated clients' health status, functional abilities, and resource utilization at baseline, six months, and twelve months. Additionally, organizational characteristics and staff experiences were surveyed to understand the structures and processes influencing care delivery (Van de Roest et al., 2019).

A key outcome of the IBenC project was the development of a benchmarking method that combined quality and cost indicators to identify six distinct home care models. These models varied in their degree of patient-centeredness, availability of specialized care professionals, and extent of performance monitoring (Van Eenoo et al., 2018). To assess performance, two summary measures were developed: the Independence Quality Scale (IQS), reflecting how well organizations maintained clients' functional independence, and the Clinical Balance Quality Scale (CBQS), evaluating improvements in clients' overall functioning (van der Roest et al., 2019).

The findings offer valuable guidance for policymakers and providers by linking organizational characteristics, care processes, and client outcomes—supporting efforts to optimize home care services and promote aging in place across different European contexts. All six participating countries—Belgium, Finland, Germany, Iceland, Italy, and the Netherlands—have policies that emphasize enabling older adults to remain at home with appropriate support and care. The IBenC project's comparative analysis across these nations contributes to understanding how different care models and national contexts influence the success of such policies and the sustainability of community-based care.

Although the findings from the IBenC project were used in this doctoral study, the focus was not on service costs, but rather on the needs of the older people and their informal caregivers as well as the formal services provided, in particular on home care nursing.

2.3 Home care nursing

With an increasing number of frail older people managing long-term illnesses at home, policies have shifted care delivery from secondary to primary care to address demographic changes (Melby et al., 2018; Norlyk et al., 2020). These changes inevitably lead to a shift in the role of home care nurses, with an increasing emphasis on organization and coordination where home care nursing is usually of central importance.

Home care is delivered by a diverse group of staff with varied educational backgrounds and skill sets. This team includes personal care aides, home health aides, nursing assistants, and nurses. In some countries, additional care providers—such as occupational therapists, dietitians, and physicians—also contribute to care delivery. Each team member plays a vital role in ensuring comprehensive and person-centred support for individuals receiving care at home (Larsson et al., 2022). While acknowledging the importance of all members of the home care team, this thesis places particular emphasis on the role of nurses, examining their contributions and responsibilities within home care specifically.

As Davina Allen observed, nurses have become key players in organizing and coordinating health and social services (Allen, 2015). Allen's theory, particularly her concept of "invisible work," offers a lens to understand the organizational contributions of nurses, which often go unrecognized in traditional healthcare metrics. In her 2015 work, Allen introduced the idea that much of nurses' work involves coordinating trajectories of care—that is, managing how care unfolds over time in response to the changing needs of patients. This theory, known as Care Trajectory Management, was later elaborated in Allen (2018), where she described how nurses orchestrate and adapt care processes in real time, often across disciplinary and institutional boundaries.

This theoretical framework is highly relevant to the current study, which investigates the home care context where older people increasingly present with complex and evolving health needs. Allen's theory supports the understanding of home care nurses as the central agents in managing this complexity. By aligning care delivery with the day-to-day realities of patients' lives and facilitating collaboration between family members and multiple health professionals, nurses enact leadership roles that are both relational and organizational.

In this study, the centrality of the nurse's coordinating role relates directly to the research aim of identifying predictors of nursing home admission and caregiver distress. These outcomes are influenced by how effectively care is managed in the home, including the nurse's ability to integrate formal and informal support systems, respond to changes in a client's condition, and ensure continuity of care. Allen's framework helps conceptualize these processes and grounds the study's interpretation of findings related to home care service structures, the distribution of tasks, and the significance of nursing leadership.

Studies of home care nursing have shown that it is both complex and unpredictable, demanding advanced skills in organization, collaboration, and clinical practice to ensure coordinated actions that align with the needs of each individual patient (Norlyk et al., 2022). In Iceland, the role of home care nurses has been described as largely relational, captured in the metaphor of creating a net around each person being cared for (Bjornsdottir, 2017); in Norway, home care nurses were described as tying up all loose ends (Melby et al., 2018); in Sweden, a spider web was used as a metaphor for the work of home care nurses (Larsson, 2024); and in Belgium, home care nurses described themselves as 'linchpins' (De Groot et al., 2018). These findings signify the central role of home care nurses in home care service teams.

As older people remain at home for longer, their needs often grow and become more complex, necessitating a multidisciplinary group of professionals. In this context, the increasing need for a broader range of professional disciplines within the home care system requires effective teamwork. Allen's theory emphasizes that nurses take the lead in ensuring that patients receive appropriate care at the right time by coordinating efforts among multiple healthcare providers, patients, and family members (Allen, 2018). Home care nurses are tasked with identifying the specific information relevant to the situation at hand and integrating services to meet the diverse needs of clients. Considering their daily contact with clients, home care nurses are uniquely positioned to coordinate multidisciplinary teams, ensuring collaboration across various professions (Allen, 2015). Therefore, nurses' leadership in home care is pivotal for ensuring effective collaboration, as they are responsible for organizing, communicating, and integrating the contributions of various professionals (Claesson et al., 2020; Larsson et al., 2022). Furthermore, Jordal et al. (2022) highlight that the leadership of nurses in home care not only fosters team cohesion but also enhances care outcomes by addressing challenges related to communication and service integration. This leadership role has grown significantly in recent years, with nurses reportedly spending up to 70% of their working time on organizational tasks, emphasizing the critical nature of their contributions to both the operational and interpersonal aspects of home care (Allen, 2015; Fjørtoft et al., 2020). These changes reflect a broader shift in the role of home care nurses, underlining their integral position in addressing the increasingly complex health challenges faced by clients.

Home care nurses provide diverse care in patients' homes, ranging from personal care and technical procedures to prevention and psychosocial support (Bjornsdottir & Ceci, 2022). Moreover, a significant part of their role also involves organization and coordination. Previous findings suggest that nurses value the variety in their work, describing themselves as 'linchpins' who lead care and operate at the centre of client support (De Groot et al., 2017). The same study by De Groot et al. (2017) also reported that home care nurses appreciate the autonomy in decision making and the self-directed nature of their teams. The variety in patient needs and activities fosters alertness, improvisation, flexibility, and creativity, as standard solutions often do not suffice (Bjornsdottir, 2014). Despite challenges such as limited resources, nurses found satisfaction in successfully overcoming these obstacles and meeting the unique demands of home care.

Increased care needs of home care clients necessitated an improvement in knowledge and competence among home care staff to address more complex and extensive care needs (Fjørtoft et al., 2020). Therefore, educating healthcare assistants to observe specific aspects of care is therefore a crucial task undertaken by home care nurses. This training is essential, as proper observation of patients' conditions and trajectories is vital for delivering high-quality care (Fjørtoft et al., 2020).

In the context of home care, Allen's (2015) theory elucidates how nurses navigate the complexities of managing patients with multiple, evolving needs while balancing limited resources. For example, nurses often assess patients' conditions, determine care priorities, and coordinate with other professionals and family caregivers. This work is critical to ensuring continuity of care and preventing unnecessary hospitalizations or nursing home admissions (Allen, 2015).

2.4 Informal caregivers

The relationship between formal and informal assistance is often indistinguishable. Informal caregivers are typically family members, friends, or neighbours, offering support to those in need without being paid. In contrast, formal care involves paid services delivered by professionals within healthcare and social service institutions (Li & Song, 2019). Informal caregivers are generally family members or friends, especially spouses or adult children, as well as children-in-law and neighbours of the care recipients (Betini, 2017). Most informal caregivers are women; they are wives, daughters, and daughters-in-law (Lopez Hartmann et al., 2019). It has been estimated that informal caregivers provide 60%–90% of home care (Pauley et al., 2018).

The aforementioned demographic changes indicate that many older people are experiencing more complex care needs, which has increased the demands on caregivers and necessitated a re-evaluation of the services provided to frail older people living at home. Advances in medical technology, reduced length of hospital stay, and increased life expectancy have further contributed to the growing complexity and duration of caregiving responsibilities (Schulz et al., 2018). Informal caregivers, who often assume this role without prior solicitation, typically perceive themselves as prepared to undertake these challenging tasks (Couto et al., 2019).

2.5 Caregiver distress

While the concept of aging in place is generally regarded as positive, it has resulted in the transfer of significant work from formal services to older people and their families. In many cases, family caregivers assume advanced healthcare tasks and assume the roles of case managers and advocates for older individuals, addressing the gaps that frequently appear in care systems characterized by fragmentated service delivery (Kim et al., 2023).

Despite their willingness and positive attitude, caregivers may often find themselves unprepared to handle the physical, emotional, psychological, and financial demands associated with the caregiving role (Couto et al., 2019). Additionally, they may lack the necessary skills to provide adequate care (Strommen et al., 2020). Caring for older people with multimorbidity, reduced functional ability, and complex care needs can be particularly challenging, frequently resulting in caregiver distress (Abey—Nesbit et al., 2021; de Almeida Mello et al., 2017).

Studies have demonstrated that being an informal caregiver can be a source of significant stress, often resulting in a sense of burden. This phenomenon is described as ‘caregiver distress’, where distress is defined as discomfort, strain, or apprehension (Ridner, 2004). The findings of Van Droogenbroeck et al. (2025) indicate that caregiver distress is more closely linked to the nature and intensity of caregiving tasks than to the demographic characteristics of the caregivers.

By identifying caregiver distress, the home care staff can identify interventions to support caregivers. One potential approach is to examine whether specific characteristics of home care clients can predict caregiver distress. Identifying these predictors makes it possible to intervene and provide caregivers with the necessary assistance and support.

2.6 A conceptual overview of the three studies in the thesis

A robust home care system is essential for supporting older people in maintaining living at home despite health and functional challenges (Contandriopoulos et al., 2022). Evaluating the clients’ physical and mental health conditions and functional abilities is critical for identifying care needs and creating tailored support plans. To create individualized care plans, home care nurses require a comprehensive overview of the client’s health and abilities. The interRAI-HC is a valuable assessment tool in this context. It provides a broad overview of the physical, mental, social, and cognitive health, functional status, sociodemographic characteristics, available resources, and care needs of older people living in the community (Barnabei et al., 2008; Landi et al., 2000; Morris et al., 1997; Salahudeen & Nishtala, 2019). It provides an opportunity for comparisons across time periods and countries. Additionally, it facilitates the identification of client-related factors that may predict caregiver distress among family caregivers and the likelihood of relocation to a nursing home.

Although some previous studies have used interRAI-HC data to examine predictors of caregiver distress and nursing home admission, most have been conducted outside of Europe or in single-country settings. Cross-national comparative research using standardized assessment tools like interRAI-HC is still limited in Europe, particularly in exploring client characteristics, health status, functional abilities, and formal care use, as well as how these factors predict caregiver distress and institutionalization among home care clients. Therefore, this study is of central importance.

While the policy focus on aging in place is well-established, there remains little comparative evidence on how health systems across Europe are supporting this goal in practice. This doctoral project helps address that gap by using harmonized data from six European countries to examine client needs, care provision, and predictors of key outcomes. The findings offer new insights into how national context may shape home care delivery and help older people remain at home longer.

This doctoral thesis includes three interrelated studies, each addressing a different but complementary aspect of home care for older people in Europe. The studies are unified by a shared focus on understanding how formal services and informal caregiving interact to support aging in place. Together, they form a cohesive narrative about who receives home care, what challenges they and their caregivers face, and which factors predict the need for institutional care. The first study takes a system-level view, examining whether the home care provided aligns with the needs of increasingly frail clients. The second study explores caregiver distress, a crucial outcome that can influence whether older people are able to remain at home. The third study focuses on clients who remained at home over a year, examining both their changing needs and the factors associated with transition to a nursing home. Together, the studies provide a layered understanding of home care delivery and contribute to a more integrated view of service design and policy across different national contexts.

3 Aims

This doctoral study aims to contribute to the development and understanding of home care services by analysing and mapping the health and physical and cognitive abilities of home care clients over time, as well as examining their care needs and those of their informal caregivers. The overarching goal is to generate knowledge that may support older people in continuing to live at home for as long as possible. The primary objective was to identify factors associated with transitions to nursing homes and contributors to caregiver distress. By identifying these risks factors, the study offers insights that can guide efforts to improve care delivery and strengthen support for both clients and their families.

This thesis consists of three interrelated studies, each addressing a different aspect of home care service challenges. Together, they provide a broader understanding of client needs, caregiver distress, and the predictors of institutionalization.

The specific aims of each study were as follows:

3.1 Paper I

Study I aimed to 1) investigate whether the health, physical and cognitive abilities, and circumstances of home care clients in five European countries changed over a ten-year period and 2) assess whether the services provided effectively addressed client needs, that is, whether those with the greatest needs received the most assistance.

3.2 Paper II

Study II aimed to 1) determine the prevalence of caregiver distress among informal caregivers in six European countries and 2) identify the client characteristics, health, physical and cognitive abilities, and circumstances that may predict caregiver distress among informal caregivers of home care clients.

3.3 Paper III

Study III aimed to 1) examine changes in health, physical and cognitive abilities, and circumstanses among home care clients who remained at home after a one-year period and 2) identify factors that may predict their admission to nursing homes in four European communities.

Together, these three studies offer complementary insights that contribute to the overall aim of the thesis. Paper I provides a system-level perspective on changes in client profiles and service provision. Paper II highlights the emotional and structural pressures faced by informal caregivers and how these relate to client needs. Paper III identifies predictors of institutionalization over time, helping to clarify which clients may be at increased risk of nursing home admission. Collectively, these findings enhance our understanding of the conditions that support aging in place and offer valuable guidance for future planning and policy development in home care.

4 Materials and Methods

This quantitative study utilizes data from a prospective longitudinal study, IBenC, conducted simultaneously in six European countries—Belgium, Finland, Germany, Iceland, Italy, and the Netherlands—between 2014 and 2016. The study focused on individuals aged 65 years and older who lived at home and received assistance from formal home care services, as well as support from family caregivers where available.

4.1 Settings

Health and home care systems in Europe vary significantly, reflecting diverse cultural, economic, and political contexts. Part of the IBenC project was to compare the context, regulations, and conditions of community care delivery for care-dependent older people across the six European countries, providing insights into the organizational differences in community care systems and the populations they serve; detailed results are reported in Van Eenoo et al., (2016). In these countries, the primary funding sources for long-term care health services are public insurance, taxation, and client co-payments. In Iceland, Finland, and Italy, these services are predominantly funded through national or municipal taxation (Genet et al., 2013). In contrast, the Netherlands and Germany primarily rely on obligatory public insurance systems (Genet et al., 2013). Belgium employs a mixed funding model, where care provided by nurses is largely financed through public insurance, whereas family care, including personal and domestic support, is primarily funded by community taxation (Genet et al., 2013).

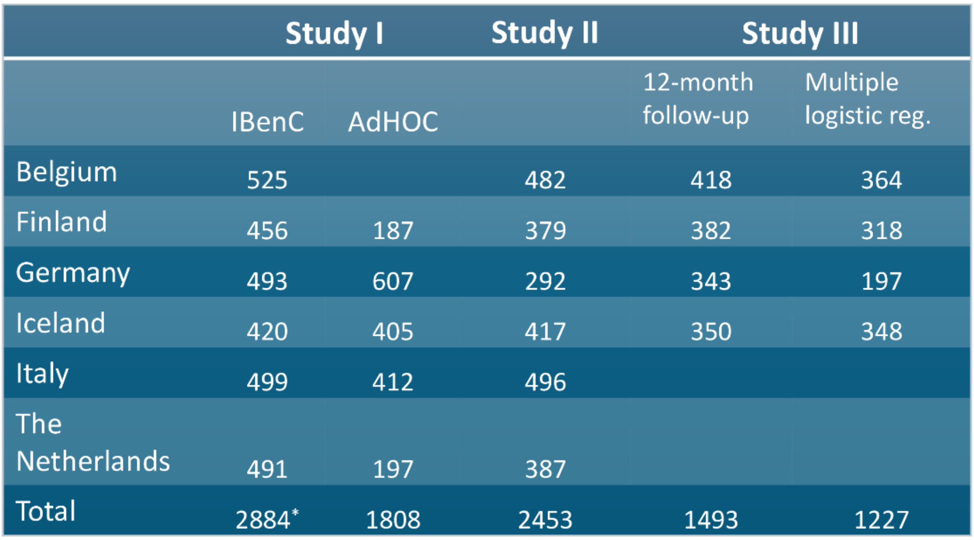
Home care organizations in selected areas of Belgium, Finland, Germany, Iceland, Italy, and the Netherlands that provided health and/or social care in the community were invited to participate in the IBenC study. A home health care organization was defined as a professional care provider offering services in the community, including nursing care (technical, supportive, or rehabilitative activities performed by nurses), personal care (assistance with activities of daily living [ADL], such as dressing, eating, personal hygiene, toilet use, and bed mobility), and/or domestic care (support with instrumental activities of daily living [IADL], such as shopping, meal preparation, housekeeping, transportation, medication management, and financial management) (Van Hout et al., 2019). For the purpose of the IBenC study, data heterogeneity was required to develop the benchmarking method. Home care organizations in the participating countries, preferably those using the interRAI-HC assessment, were selected to reflect a variety of care practices, including differences in location, size, management, and payment model. Consequently, the selection represents diverse care practices rather than being nationally representative. In Iceland, however, the sample was drawn from the entire population in the capital city Reykjavik, making it representative of home care clients in that specific region. A more detailed description of the methodology and sample in the IBenC study has been published previously (Van de Roest et al., 2019; Van Eenoo et al., 2018).

4.2 Sample

The sample comprised of 2,884 home care clients aged 65 years and older who were receiving services from 38 home care organizations across six participating European countries. The inclusion criteria were home care clients—aged 65 years and older—receiving home care from a participating organization, who were expected to remain in care for at least 6 months after enrolment. Because IBenC was a longitudinal study, it was important that clients could participate throughout the one-year study period. Clients were excluded if they had a terminal illness, were at the end stage of life, were receiving short-term care or had planned transfer to a long term institution within 6 months. If participants who had been diagnosed with moderate or severe cognitive impairment (Cognitive Performance Scale [CPS] score ≥3) did not have an informal caregiver or legal representative, they were excluded. It was considered important that cognitively impaired individuals (scoring ≥3 on the CPS scale) had a close relative, legal representative, or legal guardian who could provide consent on behalf of the home care client and reliable information in relation to the client's care utilization.

Care recipients from participating care organizations who fulfilled the inclusion criteria were informed in writing and orally about the study and invited to participate. They signed an informed consent form before joining the study. However, according to local regulations, informed consent was not required for participants receiving care from organizations using the interRAI-HC as part of routine care. For these clients, assessments were conducted by the corresponding organization's staff for clinical purposes, and the data were transferred anonymously to the national study centres (Van de Roest et al., 2019). Table 1 shows the distribution and number of participants in each study: Study I, Study II and Study III.

Table 1. Number of participants and their distribution in each study



	Study I		Study II	Study III	
	IBenC	AdHOC		12-month follow-up	Multiple logistic reg.
Belgium	525		482	418	364
Finland	456	187	379	382	318
Germany	493	607	292	343	197
Iceland	420	405	417	350	348
Italy	499	412	496		
The Netherlands	491	197	387		
Total	2884*	1808	2453	1493	1227

*The sample for 6 countries in IBenc. In the comparison between the IBenC and AdHOC studies, data from Belgium were excluded; there the sample is N=2,359

[1)]AdHOC data were obtained from Carpenter et al., 2004

4.3 Study measures

4.3.1 Study instrument interRAI—Home Care assessment

The assessment used in this study is the interRAI-HC assessment. The instrument was first developed by a team of gerontologists in the United States in the late 1980s. The interRAI-Nursing Home assessment tool was the first interRAI tool and was implemented in nursing homes in the United States in the early 1990s (Hawes et al., 1997; Morris et al., 1990). In the following years, new versions of the assessment were developed to address the needs of various sectors within the healthcare system. In 1996, the interRAI-HC instrument was introduced for the assessment of home care clients. In addition to assessing cognitive and physical abilities, this instrument lays emphasis on factors related to quality of life, individual activities, and the support provided by family caregivers (Bernabei et al., 2008; Gray et al., 2009; Hawes et al., 1997).

The interRAI-HC assessment tool is used internationally in health care settings for routine care to support assessment, care planning for vulnerable clients, and research studies. It offers a broad overview of a home care client's sociodemographic, health, functional status, resources, and service use (Morris et al., 1997). The interRAI-HC instrument provides a range of data, including circumscribed information about issues, such as hearing, vision, and ADL as well as outcomes from scales using information from multiple items to calculate a person´s risk of a specific event and levels of impairment. The scales are specifically developed for the instrument and are integral to it. They provide outcome measures among other things to track clients' clinical status over time (Morris et al., 2000).

4.3.2 Clinical scales of interRAI—Home Care

The scales developed based on the basis of data from the interRAI-HC assessment represent various clinical aspects of the client's health and condition. Previous studies have demonstrated that the items and scales of the instrument have good validity and reliability (Hirdes, et al., 2008a; Morris et al., 1997; Poss et al., 2008).

The Activities of Daily Living Hierarchy (ADLH) scale is an incremental scale used to assess functional status. It assigns fewer points to early-lost skills, such as bathing, and more points to later-lost skills, such as eating. Scores range from 0 (no impairment) to 6 (total dependence), with a score of ≥3 indicating the need for extensive ADL support (Morris et al., 1999).

The Cognitive Performance Scale (CPS) measures cognitive impairment using items such as memory issues, decision-making abilities in daily activities, communication clarity, and level of consciousness. Scores range from 0 to 6, where a score of ≥3 indicates moderate to very severe cognitive impairment (Morris et al., 1994).

The Depression Rating Scale (DRS) is a screening tool designed to assess depression risk, using items that assess mood-related behaviours such as making negative statements, persistent anger, and repetitive anxious actions. Scores range from 0 to 14, where the scores are combined in four groups: 0, 'no depression'; 1–2, 'some symptoms of depression'; 3–5, 'possible depression'; and, >6, 'possible severe depression' with higher scores representing an increased risk of depression (Burrows et al., 2000).

The Changes in Health, End-Stage Disease, and Signs, and Symptoms Scale (CHESS) identifies individuals with increased medical complexity and an increased risk of significant health decline. The scale incorporates items related to health conditions, end-stage disease, nutritional challenges, and changes in decision making and ADL status. Scores range from 0 (no health instability) to 5 (very high health instability) (Hirdes et al., 2003).

Additionally, the interRAI-HC assessment includes decision-support algorithms such as the Method for Assigning Priority Levels (MAPLe). This algorithm integrates various factors, including ADL impairment, cognitive function, behavioural issues, falls, and IADL performance, to provide a composite measure. The MAPLe scale is used to prioritize clients for community- or facility-based services and predict long-term care placement (Hirdes et al., 2008b).

4.3.3 Outcome measures

The interRAI-HC assessment tool extensively covers the health status of an individual, as well as health problems, providing an assessment of medical, psychological, social, and functional skills and care needs of participants (Barnabei et al., 2008; Landi et al., 2000; Morris et al., 1997; Salahudeen & Nishtala, 2019). In all three studies, the ADLH scale was used to assess functional status and the CPS scale to examine cognitive performance. The DRS scale was used to screen for possible depression and the CHESS scale was used to assess medical complexity and risk of severe health decline. The MAPLe scale was used to assess clients' overall condition and care needs. To measure assistance from the formal care system, the number of hours of care received during the seven days prior to the interRAI assessment was documented. This included hours provided by home care nurses, home health aides, and homemaking services (IADL). These hours were summed to create a single variable representing the total amount of formal care received, referred to in this thesis as "hours of formal care". This approach was necessary to ensure comparability across participating countries, as the organization and delivery of care tasks varied. For instance, support with activities of daily living (ADLs) might be provided by home health aides in one country and by homemaking services in another. In Iceland, for example, home care nursing and social services had already been integrated at the time of data collection. In integrated home care systems, services are delivered through interdisciplinary teamwork, where each provider contributes their unique expertise within a coordinated care plan. The total amount of formal care thus reflects the combined effort of a care team, rather than interchangeable tasks.

Study II examined caregiver distress and its predictors on the basis of the home care clients' characteristics. While the interRAI-HC assessment tool primarily gather information about older people receiving home care, it includes three items specifically addressing informal caregivers, which have been used to assess caregiver distress (Abey-Nesbit et al., 2021; Chang & Hirdes, 2015; Hirdes et al., 2012; Jamieson et al., 2019; Pauley et al., 2018). The first item assesses whether a caregiver is able to continue caregiving due to their own declining health; the second reflects the primary caregiver's reported feelings of distress, anger, or depression; and the third allows family members or close friends to report whether they feel overwhelmed by the client's illness. In Study II, caregiver distress was considered present if caregiver marked one or more of these items as true. These three items are closely related and are all considered important for identifying the informal caregiver's support system and its reserves (Abey-Nesbit et al., 2021; Hirdes et al., 2012; Jamieson et al., 2019).

4.4 Data collection

Data were collected using a prospective longitudinal design. Each home care client was assessed by trained (research) nurses, using the interRAI-HC assessment tool at baseline, after 6 months, and again after 12 months. The doctoral student was responsible for the data collection process in Iceland, including tasks such as submitting applications for permits and related activities. Additionally, the student conducted over a quarter of all the interRAI assessments performed in Iceland. The data were collected between January 2014 and August 2016. Notably, assessment errors were detected in the data collected in Italy, making the longitudinal data unsuitable for use. Therefore, it was decided to include interRAI-HC client assessments from the 6-month follow-up and retrospectively select baseline assessments (Van de Roest et al., 2019).

4.4.1 Study I

In Study I, data from the IBenC study data were compared with those from the Aged in Home Care (AdHOC) project. The results from the AdHOC study were obtained from published peer-reviewed articles (Carpenter et al., 2004; Sørbye et al., 2009), whereas the IBenC data were obtained from the IBenC database. The inclusion and exclusion criteria for participation in the AdHOC study were identical to those in the IBenC study. Additional details on the methods used in the AdHOC study are available in previously published articles (Carpenter et al., 2004; Sørbye et al., 2009). To compare between these two studies and time periods, data from the countries that participated in both studies were used: Finland, Germany, Iceland, Italy, and the Netherlands (IBenC, *N*=2,359; AdHOC, *N*=1,808). Belgium was not a participating country in the AdHOC study. For other analyses, the whole sample from IBenC was used (*N*=2,884). For Study I, only baseline data from the IBenC were used.

4.4.2 Study II

Study II examined caregiver distress among those caring for home care clients in the IBenC study. In total, 388 (13.5%) home care clients reported having no informal caregivers and were therefore excluded from the analysis in Study II. Data on informal caregivers and informal care provided were missing in the data from Belgium, which were therefore excluded from this analysis.

4.4.3 Study III

Home care clients who continued to receive home care or who moved to a nursing home during the one-year follow up period were eligible for inclusion in Study III. Data from clients who died or were discharged from home care during this period were excluded. Data from Italy were unusable, as baseline data were recorded retrospectively, 6 months after participants were enrolled in the study (Van de Roest et al., 2019). Consequently, no participants transitioned to a nursing home within the first 6 months. Data from the Netherlands were also excluded owing to data unavailability regarding the transfer of home care clients to nursing homes. Finally, 266 participants were excluded because of incomplete data, leaving data from 1,227 home care clients in the final sample.

4.5 Statistical analysis

In Studies I and II, data analyses were performed using SPSS for Windows version 26.0–28.00 (IBM Corp. Armonk, NY, USA); for Study III, R for Windows 4.3.1 and RStudio 2023.23.1. were used to conduct data analyses. The significance level for all statistical comparisons was set at $p<0.05$ (two-sided), and odds ratios (OR) were calculated with 95% confidence intervals (CI).

4.5.1 Paper I

Descriptive and inferential statistics were employed to report and analyse the characteristics of home care clients, with comparisons between countries and across study periods. Analyses focused on cognitive and physical skills, as well as comparisons of the average time of home care provided (in hours) both in the IBenC and the AdHOC studies.

Baseline data from the IBenC study were analysed to assess whether individuals with greater care needs received more home care services. The home care clients were categorized into two groups on the basis of their physical and cognitive abilities, as measured by the ADLH scale and CPS, respectively. Those with scores ≤2 were placed in the 'low' group, while those with scores of ≥3 or higher were categorized in the 'high' group. A score of ≥3 on both scales was used as the threshold for substantial care needs (Morris et al., 1994; Morris et al., 1999). Individuals scoring ≥3 on the ADLH scale were considered to require significant assistance with ADL, whereas those scoring ≥3 on the CPS were considered to have moderate-to-severe cognitive decline and in need of supervision (Morris et al., 1994; Morris et al., 1999). The amount of home care provided over 7 days preceding the evaluation was grouped into three categories on the basis of total time (in minutes): 1–139 min (minimal), 140–419 min (moderate), and ≥420 min (substantial). This classification follows customary practices in home care. Receiving less than 139 min of care in the previous week suggests that clients receive less than 20 min of care per day, indicating that they are relatively self-sufficient. Clients who receive up to 60 min of care daily are considered to need considerable support, likely requiring assistance with tasks such as dressing and bedtime routines. Those who need more than 60 min of care daily may be significantly disabled and require extensive assistance, often from two caregivers. Cross-tabulation analyses were conducted to determine whether those with higher care needs received more extensive home care than those in better physical and cognitive condition. The chi-square test was used to assess the statistical significance of differences between the groups.

Correlation analyses were conducted to explore the relationship between high scores on the ADLH scale and the CPS. Additionally, the potential impact of high scores on either the ADLH scale or CPS on the duration of home care received was investigated. Pearson's correlation coefficient was used to assess the strength and direction of these relationships.

4.5.2 Paper II

Descriptive statistics were used to outline the characteristics of the sample, including the percentage of informal caregivers experiencing caregiver distress. Cross-tabulation analysis was used to examine the prevalence of caregiver distress across different conditions and client characteristics, with chi-square tests applied to assess differences between groups at a significance level of $p<0.05$. T-tests were performed to investigate the effect of continuous variables, such as age and hours of formal care, on caregiver distress, using the same significance threshold. The primary outcome, distinguishing between distressed and non-distressed caregivers, was analysed using binary logistic regression to calculate odds ratios (OR) and 95% confidence intervals (CI).

The selection of variables for the multiple regression model was guided by previous studies identifying predictors of caregiver distress, particularly those using the interRAI-HC instrument (Abey-Nesbit et al., 2021; Chang & Hirdes, 2015; Hirdes et al., 2012; Jamieson et al., 2019; Pauley et al., 2018). Commonly reported predictors include the cognitive and functional status of care recipients, the amount of formal and informal care provided, and the living arrangements between caregiver and care recipient. Based on these findings, the following measures from the interRAI-HC dataset were included in the model: age and gender of the client; whether the caregiver lived with the client; scores on the DRS, CPS, MAPLe, and CHESS scales; presence of bladder incontinence; recent hospital admission; hours of formal care received; and whether the client had engaged in physical activity in the three days preceding the assessment. Variables that were statistically significant in any of the participating countries were considered for inclusion in the multiple logistic regression model. This multiple approach enabled control for potential confounders and the identification of complex relationships between predictors, thereby offering a deeper understanding of their impact on the outcome. Caregiver distress served as the dependent variable, and the significant variables hypothesized to influence distress were treated as independent variables.

4.5.3 Paper III

Descriptive statistics were applied to summarize the baseline characteristics of the sample, along with the proportion of clients discharged from home care and the reasons for their discharge throughout the one-year study period. To assess changes in clients' physical and cognitive health, care needs, and the duration of home care received (in hours) over the course of one year, means and standard deviations were calculated for each variable at three time points (baseline and 6 and 12 months) during the study period. These measures were calculated separately for each country and then compared using repeated measures ANOVA. This analysis did not aim to develop predictive models or assess system-level differences across countries, but rather to descriptively examine how home care clients' health, function, and formal care changed over time within their respective care systems.

Home care clients were categorized into two groups: 1) those who continued to receive home care after the one-year study period, and 2) those who had moved to a nursing home during the same period. Comparisons between these groups were made using baseline data (wave 1), while information regarding nursing home admissions was collected from waves 2 (after 6 months) and 3 (after 12 months). Differences between the groups were evaluated on the basis of various client conditions and characteristics. A chi-square test was used to assess between-group differences with a significance level of $p<0.05$, and t-tests were performed to determine whether continuous variables such as age, scores on specific scales, and hours of formal care, influenced the likelihood of moving to a nursing home, with the same significance threshold applied.

Univariable logistic regression analyses were conducted to identify variables for inclusion in the multiple logistic regression model, with the outcome being 'still receiving home care' versus 'moved to a nursing home'. Variables that reached a significance level of $p<0.05$ in either individual countries or across all four countries were considered for inclusion (Appendix A). Subsequently, backward selection was used to refine the multiple logistic regression model. The variables that remained statistically significant after backward selection included age, caregiver distress, the client's or caregiver's belief that the client would be better off living elsewhere, a high score on the ADLH scale, the number of hours of formal care the client received, and the client's belief that their physical function could improve. These variables, along with gender, were included as independent variables in the multiple logistic regression model, with the transition to a nursing home (i.e., moving vs. continuing to receive home care) as the dependent variable.

4.6 Ethics

Ethical approval for the IBenC study was obtained from authorized medical ethical committees according to local regulations in each the participating country. Iceland: Vísindasiðanefnd, No. 13–176-S1; Belgium (Flanders): Commissie Medische Ethiek van de Universitair Medische Ziekenhuizen Katholieke Universiteit Leuven, No. ML10265; Finland: Tutkimuseettinen työryhmä, No. THL/796/6.02.01/ 533/2014; Germany: Ethikkommission des Institut für Psychologie und Arbeitswissenschaft der Technische Universtität Berlin, No. GH_01_20131022; Italy: Comitato Etico Università Cattolica del Sacro Cuore, No. 2365/14; The Netherlands: Medical Ethics Review Committee VU University Medical Center, No. 2013.333 (Van de Roest et al., 2019).

Ethical approval for this PhD project was obtained in accordance with Icelandic law and the Helsinki Declaration. The study received approval from the National Bioethics Committee (No. 13–176-V1) and the Data Protection Authority (reference number: 2013111454AT). Access to the interRAI database in Iceland was granted by the Directorate of Health. Additionally, a declaration of cooperation with the doctoral student was signed by the Home Care Center in Reykjavik, Iceland.

5 Results

This chapter provides a summary of the results from the three studies. Detailed results are reported in the respective articles (Papers I, II, and III).

5.1 Paper I - Changes in home care clients' characteristics and home care in five European countries from 2001 to 2014: comparison based on interRAI - Home Care data

5.1.1 Changes in characteristics of home care clients and home care services over 10 years

Table 2 presents an overview of the sample in the two studies AdHOC and IBenC. The IBenC study included 2,884 participants, whereas the AdHOC study had 1,808 participants, across five countries. The average age of participants was significantly lower ($p<0.05$) in the AdHOC study (81.0 years) than in the IBenC study (83.0 years). Moreover, the proportion of female participants was significantly higher ($p<0.05$) in the AdHOC study (73.0%) than in the IBenC study (66.9%). Within the IBenC study, the proportion of female participants was similar across countries, with Italy having the lowest percentage at 57.3%. On average, most participants in both studies lived alone: 54.3% in the AdHOC study and 59.4% in the IBenC study. However, there was considerable variation between countries, with Italy having the lowest percentage (16.4%) and Finland the highest (80.9%) in the IBenC study. These differences between the studies were statistically significant ($p<0.05$).

Table 2. Characteristics of the home care clients in IBenC and AcHOC studies

	Belgium		Finland		Germany		Iceland		Italy		the Netherlands		All		
	AcHOC[1]	IBenC	AcHOC[2]	IBenC	AcHOC[2]	IBenC	AcHOC[2]	IBenC	AcHOC[2]	IBenC	AcHOC[2]	IBenC	AcHOC	IBenC	IBenC[3]
Study sample - (n)		(525)	(187)	(456)	(607)	(493)	(405)	(420)	(412)	(499)	(197)	(491)	(1808)	(2884)	(2359)
Female - % (n)		67.0 (352)	82.2 (154)	68.6 (313)	74.7 (453)	71.2 (351)	74.1 (300)	69.5 (292)	63.1 (260)	57.3 (286)	77.3 (152)	68.4 (336)	73.0 (1319)	66.9 (1930)	66.9 (1578)
Living alone - % (n)		48.0 (252)	83.8 (157)	80.9 (369)	62 (375)	73 (359)	68.2 (276)	61.0 (256)	12.8 (53)	16.4 (82)	61.6 (121)	68.8 (338)	54.3 (982)	57.4 (1656)	59.4 (1404)
Age, years - mean (SD)		82.4 (6.7)	81.2 (7.7)	82.7 (7.0)	81.3 (7.9)	84.2 (7.6)	81.4 (7.6)	83.7 (7.0)	80.2 (8.0)	81.8 (7.9)	80.4 (6.7)	82.5 (7.1)	81.0 7.6	83.0 (7.3)	83.0 (7.4)
CPS score - mean (SD)		1.4 (1.6)	0.7 (1.0)	1.3 (1.2)	1.4 (1.8)	1.6 (1.7)	0.6 (1.0)	1.1 (1.2)	2.0 (2.0)	2.4 (2.1)	1.0 (1.1)	0.6 (0.9)	1.1 (1.2)	1.4 (1.6)	1.4 (1.6)
ADLH score - mean (SD)		3.2 (1.2)	0.2 (0.9)	0.8 (1.3)	1.6 (1.8)	2.2 (1.7)	0.2 (0.7)	0.6 (1.1)	2.8 (2.0)	3.8 (1.7)	0.2 (0.8)	0.5 (1.1)	1.0 (0.7)	1.9 (2.0)	1.6 (1.9)
Hours of formal care - mean (SD)		8.5 (7.8)	2.2 (1.0)	5.1 (5.2)	2.7 (0.8)	7.5 (6.9)	2.2 (0.9)	3.6 (3.8)	1.3 (0.7)	1.0 (2.6)	2.6 (0.9)	4.6 (4.7)	2.2 (0.8)	5.1 (6.1)	4.4 (4.6)

[1] Belgium did not participate

[2] AdHOC data were obtained from Carpenter et al., 2004

[3] IBenC without Belgium

5.1.2 Comparison of physical and cognitive abilities between the AdHOC and IBenC studies

The mean CPS and ADLH scales scores of home care recipients, which indicate the physical and cognitive abilities, were significantly higher ($p<0.05$) in 2014 (IBenC) than in 2001 (AdHOC), (Figure 1). The CPS score (in 2014) was higher across all countries, except for the Netherlands, where it was lower; in fact, the Netherlands reported the lowest CPS score (0.6) in 2014, whereas Italy had the highest CPS score (2.4). Similarly, the mean score on the ADLH scale was significantly higher ($p<0.05$) in the IBenC study (1.6) than in the AdHOC study (1.0). In the IBenC study, home care clients in Italy scored the highest on both the physical and cognitive scales (Figure 1), indicating the highest care needs, whereas clients in Iceland and the Netherlands showed the lowest levels of cognitive and functional decline. These results are consistent with the findings from the AdHOC study.

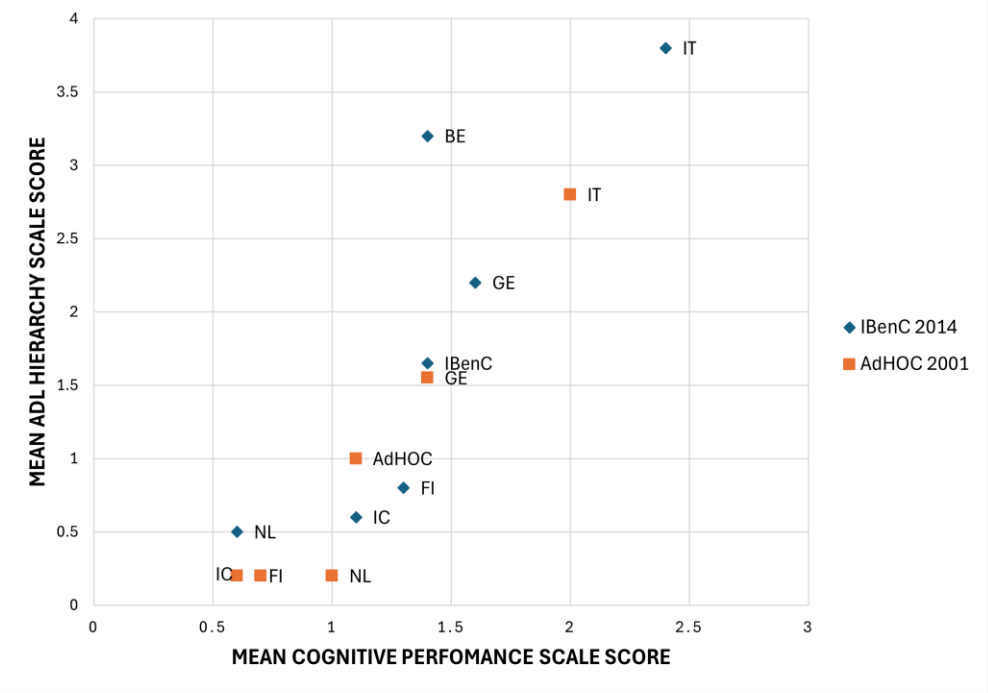


Figure 1. Changes in mean Cognitive Performance Scale score and mean ADL Hierarchy scale score by country in the AdHOC and IBenC studies.

BE=Belgium, FI=Finland, GE=Germany, IC=Iceland, IT=Italy, NL=the Netherlands.
AdHOC=mean values in the AdHOC study, IBenC=mean values in the IBenC study
AdHOC=AgeD in the Home Care
IBenC= Identifying Best Practices for Care-Dependent Elderly by Benchmarking Costs and Outcomes of Community Care
AdHOC data were obtained from Carpenter et al., 2004

5.1.3 Average hours of formal care provided to home care clients in one week

The duration of home care nursing and social services provided over 7 days preceding the interRAI-HC assessment was significantly higher (*p*<0.05) in the IBenC study (4.4 hours) than in the AdHOC study (2.2 hours). The shortest duration of home care was recorded in Italy (1.0 hour), whereas the longest duration was observed in Belgium (8.5 hours), (Figure 2).

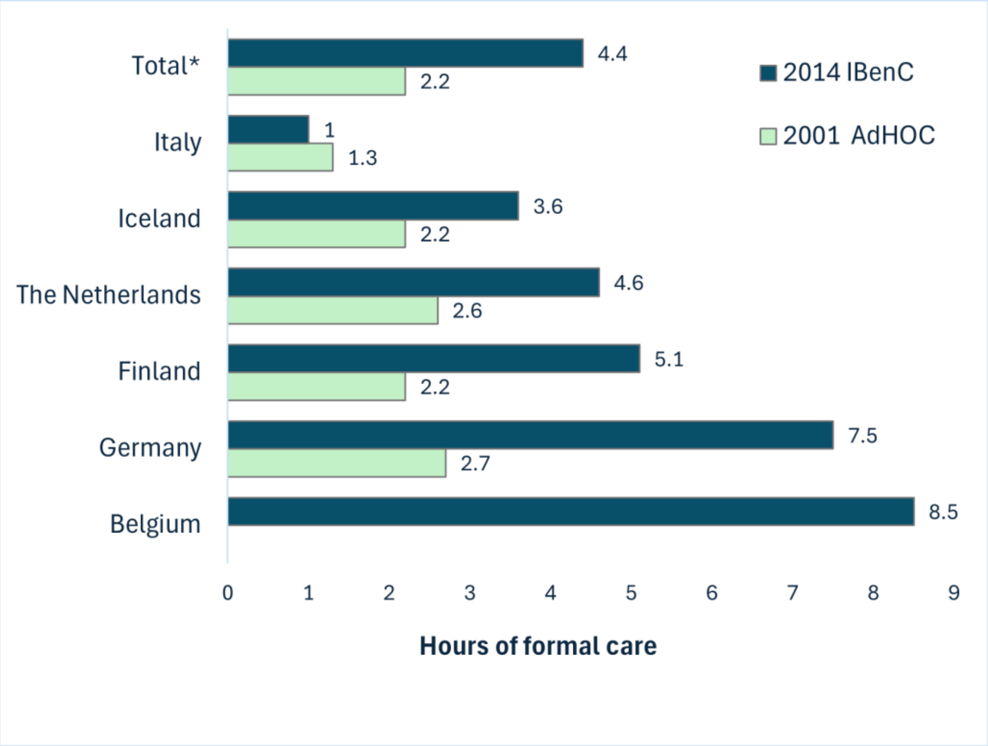


Figure 2. Duration of formal care (in hours) over 7 days preceding evaluation.

Differences between countries and studies were considered significant at *p*<0,05

* Total for Italy, Iceland, the Netherlands, Finland and Germany. Belgium did not participate in the AdHOC study.

AdHOC data were obtained from Carpenter et al., 2004

t-test *p*<0,05

5.1.4 Physical impairment and average duration of hours of home care assistance

A cross-tabulation analysis of ADLH scale scores and the duration of home care received (Figure 3) revealed a significant relationship ($p<0.05$) between physical impairment and the level of assistance provided by home care services. The results showed that more than half of those with severe physical impairment received substantial home care (≥60 min/day on average), whereas 30% and 18% received moderate assisstance (20–59 min/day on average) and minimal assistance (≤20 min/day on average), respectively. Over 20% of individuals without severe physical impairment still received substantial care. Cross-tabulation analyses conducted for each country showed a significant association ($p<0.05$) between severe physical impairment and the receipt of substantial home care in Iceland, Finland, Belgium, and Germany (Figure 4). In Germany, 88% of those with high ADLH scores received substantial care, whereas 12% received moderate assistance. In Iceland and Finland, 62% of individuals with high ADLH scores received substantial care, whereas 24% and 29% received moderate assistance, respectively, and 9% and 14% received minimal assistance, respectively.

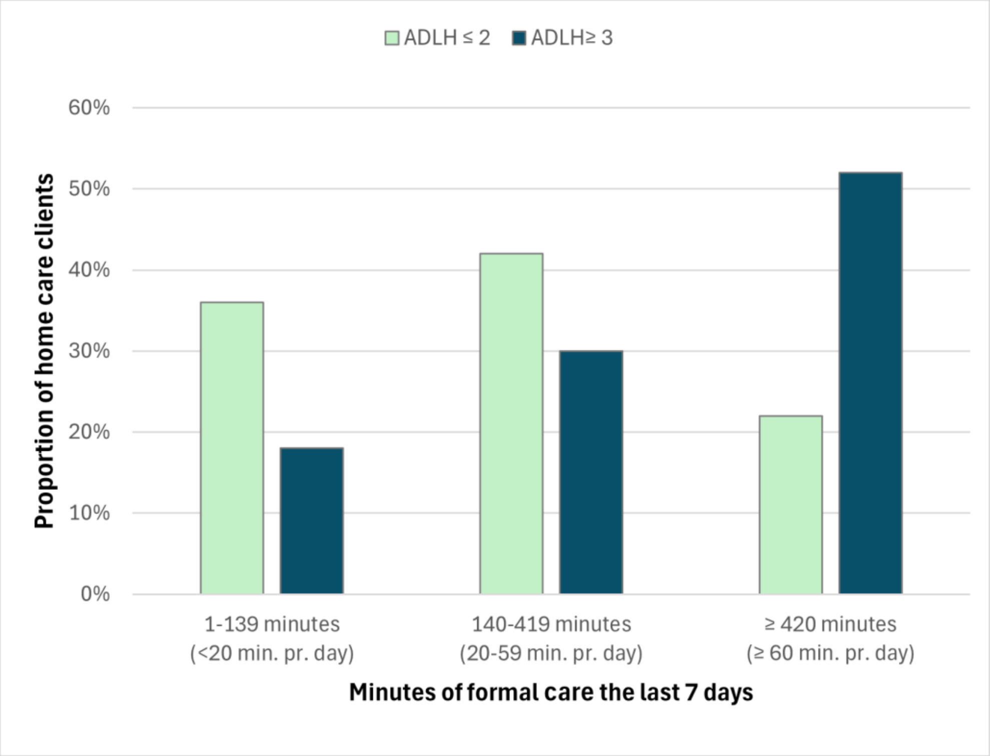


Figure 3. Relationship between ADLH scale scores and the mean total duration of formal care received (in minutes) over the 7 days preceding the evaluation across all countries in the IBenC study.

ADLH=Activities of Daily Living Hierarchy scale

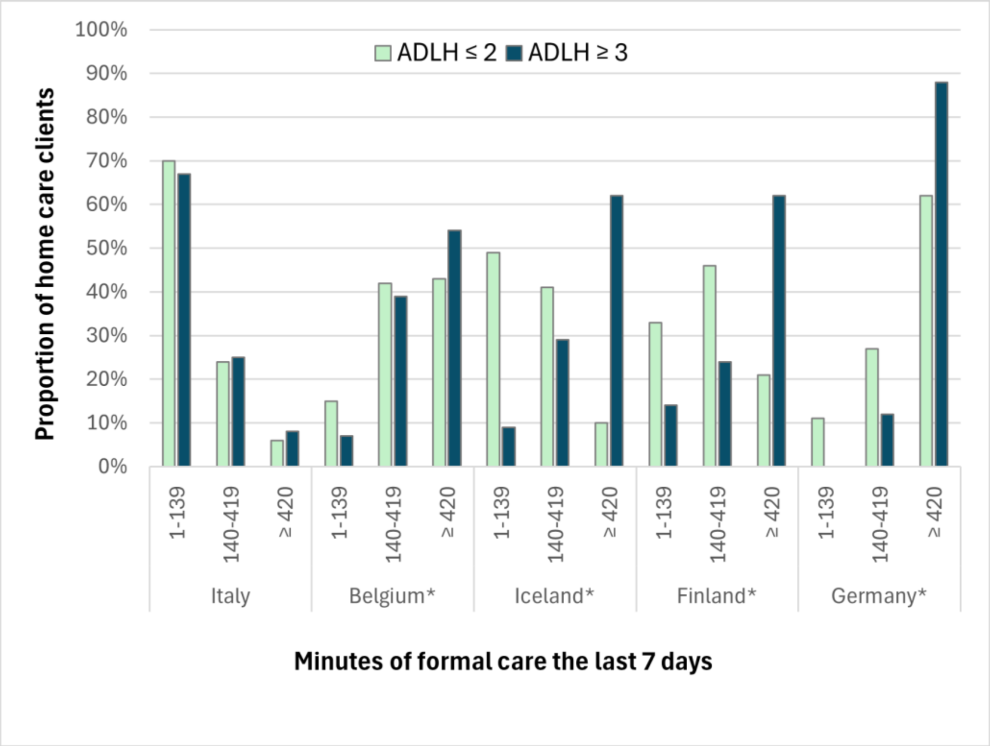


Figure 4. Relationship between ADLH scale score and the mean total duration of formal care received (in minutes) over the 7 days preceding the evaluation for each country in the IBenC study.

ADLH=Activities of Daily Living Hierarchy scale
*Significant Chi-square test *p*<0,05

5.1.5 Cognitive impairment and average duration of home care assistance

The duration of home care received was significantly higher for clients with moderate-to-severe cognitive impairment than for clients with lower scores on the CPS (*p*<0.05), as shown in Figure 5. Cross-tabulation analysis conducted for each country individually (Figure 6) revealed a significant positive relationship (*p*<0.05) between the severity of cognitive impairment and the duration of home care assistance in Iceland, Finland, and Germany. In Germany, home care clients received more assistance than clients in other countries, regardless of the severity of their cognitive impairment. In Iceland, 30%, 46%, and 24% of home care clients with severe cognitive impairment received substantial, moderate, and minimal care, respectively. In Italy, only 10% of those with severe cognitive decline received substantial home care. Data from the Netherlands were not analysed owing to the extremely low number of responses. A significant, moderately positive correlation (*r*=0.447, *p*>0.05) was found between high scores on the ADLH scale and CPS. Additionally, a significant but weak positive correlation (*r*=0.349, *p*>0.05) was observed between high ADLH scale scores and receiving substantial home care, whereas the correlation between the CPS scores and duration of home care received was very weak (*r*=0.154, *p*>0.05).

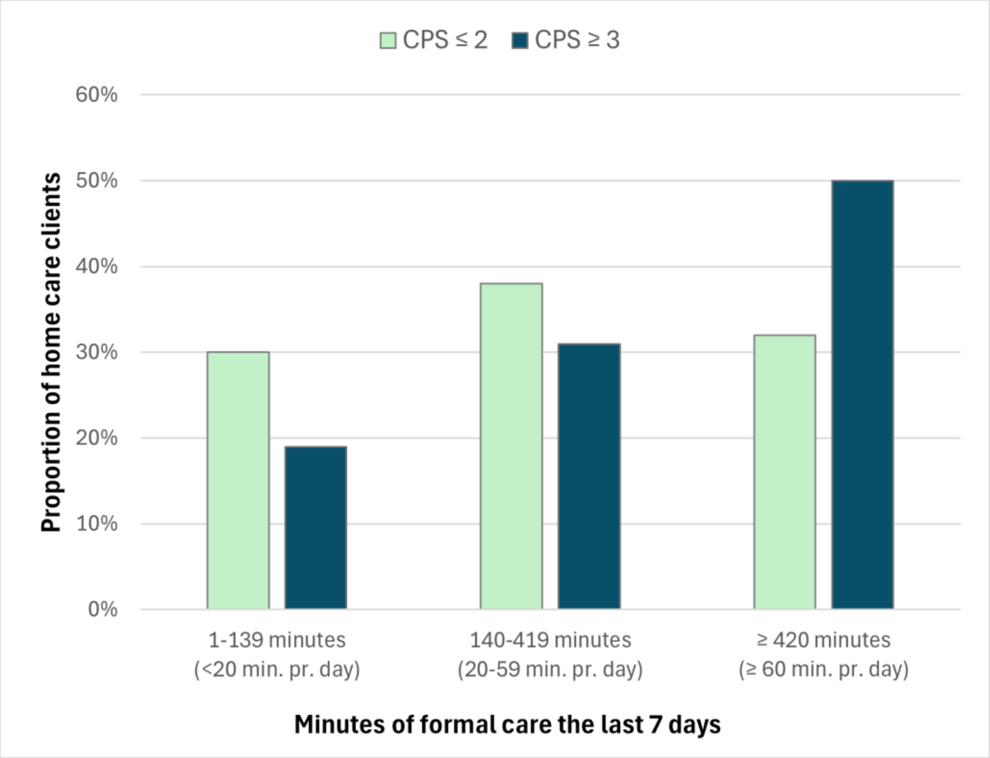


Figure 5. Relationship between CPS scores and the mean total duration of formal care received (in minutes) over the 7 days preceding the evaluation across all countries in the IBenC study

CPS=Cognitive performance scale

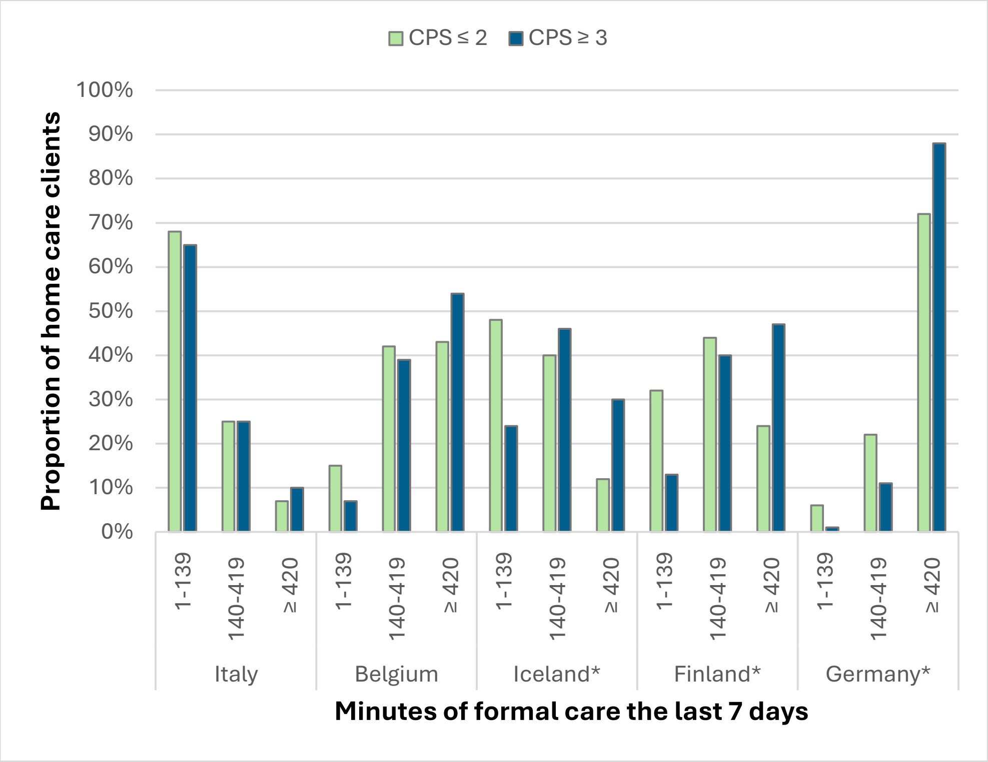


Figure 6. Relationship between CPS score and the mean total duration of formal care received (in minutes) over the 7 days preceding the evaluation for each country in the IBenC study.

CPS=Cognitive performance scale
*Significant Chi-square test *p*<0,05

5.2 Paper II - Prevalence and Predictors of Caregiver Distress in Six European Communities: data from the IBenC study, using interRAI-Home Care assessments

5.2.1 Demographic characteristics of home care clients with informal caregiver

Table 3 presents the characteristics of the 2,453 study participants with informal caregivers and their distribution across the participating countries. The average age of participants across the six countries was 83.1 years. Most participants were female (67.3%), with the lowest percentage of womed in Italy (57.5%) and the highest percentage of women in the Netherlands and Finland (71.3% and 71.2%, respectively). Over a third of participants (33.9%) were married, whereas more than half (53%) lived alone, with proportions ranging from 16.3% in Italy to 78.1% in Finland. On average, 41.2% of caregivers lived with the clients, with this value varying from 12.1% in Finland to 67.7% in Italy. In 60.7% of cases, the caregiver was a child or child-in-law of the client, spouses accounted for 25.8% of caregivers, and 13.5% were other familial connections. Informal caregivers in Italy provided the most care, averaging around 23 hours over 3 days before the assessment. In contrast, caregivers in Finland provided an average of nearly 6 hours of care, whereas an average of approximately 8 hours of care was reported in other countries. The average scores on various scales from the interRAI-HC assessment varied between countries. Home care clients in Germany, Belgium, and Italy had the highest average scores on the ADL and cognitive scales, indicating greater impairments in their abilities.

Table 3. Characteristics of the home care clients with an informal caregiver

	Belgium		**Finland**		**Germany**		**Iceland**		**Italy**		**The Netherlands**		**All countries**	
	%	n	%	n	%	n	%	n	%	n	%	n	%	n
Study sample - n		482		379		292		417		496		387		2453
Age, years - mean (SD)	82.5	(6.7)	83.5	(6.6)	84,7	(7.0)	83.7	(7.0)	81.9	(7.9)	82.8	(7.2)	83.1	(7.2)
Female	66,8	(320)	71.2	(270)	70.5	(206)	69.8	(291)	57.5	(285)	71.3	(276)	67.3	(1648)
Married	36,6	(172)	17,7	(67)	34.2	(100)	30.7	(128)	45.0	(202)	38.1	(94)	33.9$^{5)}$	(763)
Living alone	47,6	(226)	78.1	(296)	61.0	(178)	60.9	(254)	16.3	(81)	67.4	(261)	53.0$^{6)}$	(1296)
ICG$^{1)}$ lives with the client	59,4	(262)	12.1	(46)	31.5	(92)	34.3	(143)	67.7	(336)	29.7	(115)	41.2$^{7)}$	(994)
Informal caregiver														
Spouse	30,7	(148)	11.3	(43)	26.7	(78)	26.9	(112)	30.0	(149)	26.9	(104)	25.8	(634)
Child or child-in-law	55,4	(267)	69.9	(265)	59.2	(173)	61.2	(255)	61.9	(307)	57.4	(222)	60.7	(1489)
Other$^{2)}$	13,9	(67)	18.7	(71)	14.0	(41)	12.0	(50)	8.1	(40)	15.8	(61)	13.5	(330)
Caregiver distress	27,7	(133)	9.2	(35)	13.7	(40)	34.1	(142)	22.2	(110)	16.8	(65)	21.4	(525)
Informal care provided$^{3)}$ - mean (SD)	NA		5.9	(13,5)	8.3	(14,0)	8.8	(14,8)	23.2	(17,2)	7.9	(14,2)	11.6	(16,4)
ADLH score - mean (SD)	3.2	(1.2)	0.8	(1.4)	2.2	(1.7)	0.6	(1.1)	3.9	(1.7)	0.5	(1.2)	2.0	(1.9)
CPS score - mean (SD)	1.4	(1.6)	1.4	(1.2)	1.5	(1.7)	1.1	(1.2)	2.4	(2.1)	0.7	(0.9)	1.4	(1.6)
CHESS score - mean (SD)	1.1	(1.0)	0.7	(0.9)	0.6	(0.9)	1.2	(1.0)	1,6	(1.3)	1.3	(1.0)	1.1	(1.1)
DRS score - mean (SD)	1.8	(2.5)	1.0	(1.9)	1.5	(2.7)	1.2	(1.8)	1.3	(2.0)	1.7	(2.2)	1.4	(2.2)
MAPLe score - mean (SD)	3.5	(0.8)	3.3	(1.3)	3.4	(1.1)	3.0	(1.3)	3.7	(0.8)	2.5	(1.4)	3.2	(1.2)
PAIN scale score - mean (SD)	0.8	(0.9)	1.0	(1.0)	0.7	(0.9)	1.0	(1.0)	0.7	(0.9)	1.0	(1.2)	0.9	(1.0)
Hours of formal care$^{4)}$ -mean (SD)	8.8	(7.7)	5.3	(5.3)	5.8	(5.4)	3.6	(3.8)	1.0	(2.7)	5.0	(4.9)	4.8	(5.8)

Data are presented as percentages and numbers unless otherwise indicated

[1] Informal Caregiver; [2] Other=sibling, other relative, friend and neighbor; [3] average hours over the last 3 days; [4] on average last 7 days ; [5] ratio of 2254 responses; [6] ratio of 2446 responses; [7] ratio of 2412 responses

ADLH=Activities of Daily Living Hierarchy; CPS=Cognitive Performance Scale; CHESS = Changes in Health, End-Stage Disease and Signs and Symptoms; DRS=Depression Rating Scale; MAPLe = Method for Assigning Priority Levels

5.2.2 Prevalence of caregiver distress

Figure 7 illustrates the prevalence of caregiver distress among informal caregivers of home care clients. The highest percentage was observed in Iceland (34%), followed by Belgium (28%), Italy (22%), the Netherlands (17%), Germany (14%), and Finland (9%). Responses to each of the three items concerning informal caregivers varied by country. The highest response rate for a single item (32%) was reported in Iceland for the statement: 'Primary informal helper expresses feelings of distress, anger, or depression'. The highest response rate (16%) for the statement 'Informal helper(s) is unable to continue caregiving activities—e.g., decline in health of helper makes it difficult to continue' was observed in Belgium, whereas the highest response rate (10%) for the statement 'Family or close friends report feeling overwhelmed by the person's illness' was observed in both Iceland and Italy.

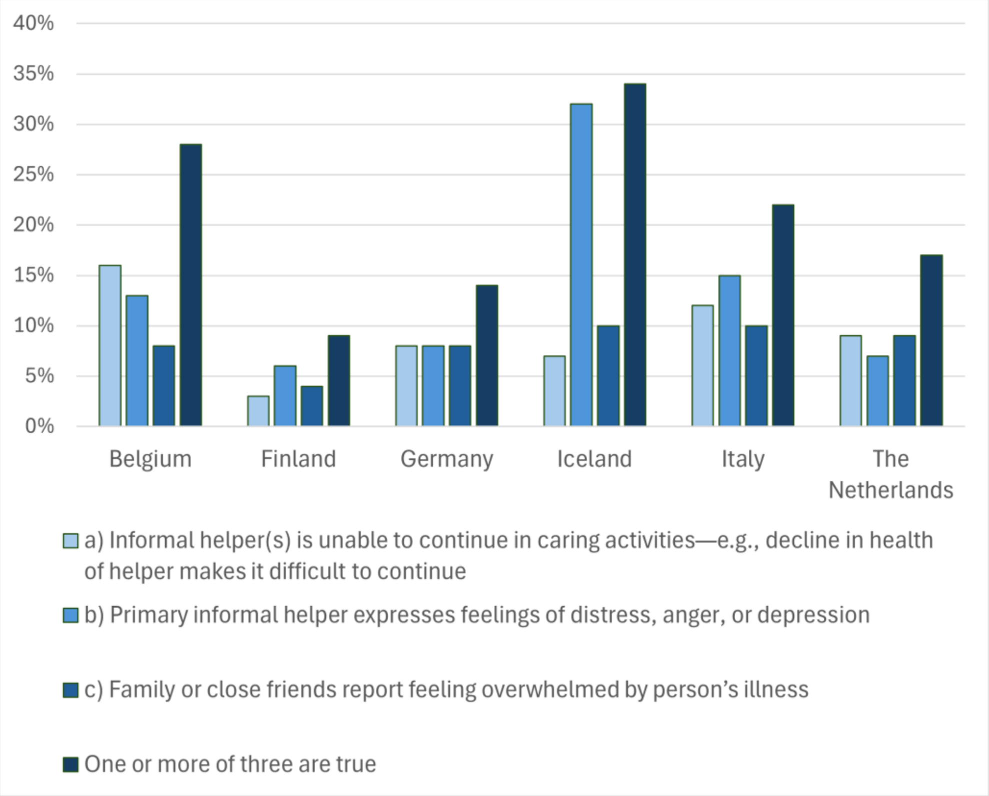


Figure 7. Prevalence of caregiver distress. Percentage of responding YES to each statement separately and responding YES to one or more of the three statements

5.2.3 Sociodemographic and health characteristics of home care clients with distressed and non-distressed caregivers

Table 4 presents the sociodemographic and health characteristics of home care clients, stratified by those with a distressed caregiver and those with a non-distressed caregiver. The factors predicting caregiver distress varied significantly across the six countries. The proportion married home care clients was higher among those with a distressed caregiver than among those with non-distressed caregivers, with a statistically significant difference observed in all countries except Finland. Furthermore, higher prevalence of caregiver distress was observed when they lived with the home care clients, a finding that was significant in all countries except Italy. Similarly, in Germany, Iceland, and the Netherlands, caregiver distress was more common when informal caregivers provided 10 hours of care during the 3 days before the interRAI-HC assessment. The presence of bladder or bowel incontinence in the care recipient as well as higher scores on the ADLH scale, CPS, and DRS (≥3) or on the MAPLe scale (≥4) were associated with a higher likelihood of caregiver distress. However, the statistical significance of these associations differed by country (Table 4). The proportion of home care clients hospitalized in the past 90 days was higher among those with distressed informal caregivers compared to those with non-distressed caregivers. This difference was statistically significant in Finland, Iceland, and Italy. Additionally, home care clients received more hours of formal care on average when caregiver distress was present, than when it was absent, with this difference being statistically significant in Finland, Iceland, Italy, and the Netherlands.

Table 4. Characteristics of home care clients stratified by the presence or absence of caregiver distress

	Belgium (482)				**Finland** (379)				**Germany** (292)				**Iceland** (417)				**Italy** (496)				**The Netherlands** (387)				**All** (2453)					
	WDC		NDC		WDC		NDC		WDC		NDC		WDC		NDC		WDC		NDC		WDC		NDC		WDC		NDC		Total	
	%	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%	(n)
Age - mean (sd)	80.9**	(6.4)	83,2	(6.7)	82,7	(6.8)	83,6	(6.6)	83,3	(8.1)	84,9	(6.8)	83,5	(7.2)	83,8	(7.0)	80.3*	(8.0)	82,3	(7.8)	81,7	(8.0)	83,1	(7.0)	81.9**	(7.4)	83,4	(7.1)	83,1	(7.2)
Female	64,1	(84)	67,7	(235)	60,0	(21)	72,4	(249)	62,5	(25)	71,8	(181)	61.3*	(87)	74,2	(204)	45.5*	(50)	60,9	(235)	63,1	(41)	73,0	(235)	58.9**	(308)	69,5	(1339)	67,3	(1647)
Married	46.9*	(61)	32.7	(111)	25.7	(9)	16.9	(58)	65.0*	(26)	29.4	(74)	39.4*	(56)	26.2	(72)	59.6**	(59)	40.9	(143)	55.3*	(26)	34.0	(68)	41.8**	(237)	29.9	(526)	33.9	(763)
Primary caregiver lives with the HC-client	69.8*	(88)	55.2	(174)	25.7*	(9)	10.8	(37)	57.5*	(23)	27.4	(69)	41.5*	(59)	30.5	(84)	73.6	(81)	66.1	(255)	44.6*	(29)	26.7	(86)	55.8**	(289)	37.2	(705)	41.2	(994)
Informal help ≥10 hours last 3 days	NA				20.0	(7)	11.3	(39)	47.5*	(19)	18.7	(47)	32.4**	(46)	17.5	(48)	80.9	(89)	73.0	(284)	35.4**	(23)	14.6	(47)	46.8**	(184)	29.4	(465)	32.9	(649)
ADLH score ≥3	87.6	(113)	83.4	(287)	28.6*	(10)	13.4	(46)	67.5*	(27)	44.0	(111)	12.7*	(18)	6.2	(17)	84.1	(90)	79.4	(296)	10.8	(7)	9.3	(30)	51.2**	(265)	41.2	(787)	43.3	(1052)
CPS score ≥3	30.1**	(37)	14.0	(48)	31.4**	(11)	9.6	(33)	32.5	(13)	21.8	(55)	19.0**	(27)	4.7	(13)	40.2	(43)	36.5	(136)	3.1	(2)	2.2	(7)	26.0**	(133)	15.3	(292)	17.6	(425)
CHESS score ≥3	10.2	(12)	7.7	(26)	20.0**	(7)	4.1	(14)	5.0	(2)	4.8	(12)	21.1**	(30)	3.3	(9)	31.8	(34)	26.0	(97)	16.9	(11)	9.9	(32)	18.9**	(96)	10.0	(190)	11.9	(286)
DRS score ≥3	37.5**	(48)	21.7	(75)	37.1**	(13)	11.6	(40)	42.5*	(17)	19.4	(49)	28.9**	(41)	11.3	(31)	32.7*	(35)	19.0	(71)	43.1**	(28)	21.7	(70)	35.2**	(182)	17.6	(336)	21.3	(518)
Maple score ≥4	59.0**	(62)	39.5	(120)	57,1	(20)	43.9	(150)	48.7	(19)	36.7	(91)	59.2**	(84)	27.3	(75)	60.8	(31)	59.0	(82)	31.1	(19)	22.3	(69)	54.3**	(235)	36.3	(587)	40.1	(822)
PAIN scale score ≥ 2 [1)]	14.6	(19)	20.8	(70)	25.7	(9)	28.5	(98)	20.0	(8)	23.0	(58)	34.5	(49)	32.4	(89)	21.8	(24)	20.7	(80)	33.8	(22)	33.2	(107)	25.1	(131)	26.2	(502)	26.0	(633)
Bladder incontinence	86.3*	(113)	77.5	(268)	62,9*	(22)	39.6	(127)	65.0*	(26)	49.6	(125)	55.6**	(79)	36.7	(101)	68.2	(75)	64.8	(250)	52.3	(34)	44.7	(144)	66.7**	(349)	52.7	(1015)	55.7	(1364)
Bowel incontinence	62.4**	(83)	45.7	(158)	17.1	(6)	14.0	(48)	45.0*	(18)	22.6	(57)	14.8*	(21)	7.6	(21)	47.3	(52)	46.6	(180)	18.5	(12)	12.7	(41)	36.6**	(192)	26.2	(505)	28.4	(697)
Nutritional problem	34.1*	(45)	21.5	(74)	0	(0)	2.9	(10)	20.0*	(8)	9.5	(24)	3.5	(5)	3.6	(10)	30.9	(34)	31.1	(120)	7.7	(5)	7.8	(25)	18.5*	(97)	13.7	(263)	14.7	(360)
Dyspnoea at rest	5.3	(7)	2.6	(9)	0	(0)	0.6	(2)	2.5	(1)	2.8	(7)	5.6	(8)	2.9	(8)	4.5	(5)	5.4	(21)	10.8	(7)	8.7	(28)	5.4	(28)	3.9	(75)	4.2	(103)
Hospital admission in the last 90 days	16.5	(22)	10.9	(38)	37.1*	(13)	21.8	(75)	17.5	(7)	13.1	(33)	34.5**	(49)	16.0	(44)	56.4*	(62)	45.1	(174)	15.4	(10)	10.6	(34)	31.0**	(163)	10.7	(398)	22.9	(561)
≥2 hr of physical activities in the last 3 days	15.5	(20)	9.5	(33)	5.7	(2)	18.6	(64)	10.0*	(4)	27.4	(69)	6.3*	(9)	16.7	(46)	0.9	(1)	0.3	(1)	32.3	(21)	34.2	(110)	11.0**	(57)	16.9	(323)	15.6	(380)
Client uses phone with assistance	47.4**	(63)	27.3	(95)	34.3*	(12)	16.0	(55)	32.5*	(13)	19.4	(49)	12.0*	(17)	4.0	(11)	70.9	(78)	64.5	(249)	7.7	(5)	6.5	(21)	35.8**	(188)	24.9	(480)	27.2	(668)
Daily nurse monitoring last 7 days	76.7*	(102)	80.5	(280)	5.7	(2)	11.3	(39)	47.5	(19)	61.1	(154)	2.8	(4)	2.9	(8)	2.7	(3)	0.8	(3)	12.3	(8)	5.3	(17)	26.3	(138)	26.0	(501)	26.1	(639)
Hours of formal care - mean (sd)	8.9	(7.1)	8.7	(8.0)	9.2**	(8.7)	4.9	(4.7)	6.7	(6.0)	5.7	(5.3)	4.4**	(4.2)	3.1	(3.5)	1.5*	(3.6)	0.9	(2.3)	6.5*	(6.0)	4.7	(4.6)	5.7**	(6.3)	4.6	(5.6)	4.8	(5.8)

WDC = With Distressed Caregiver

NDC = Not Distressed Caregiver

ADLH = Activities of Daily Living Hierarchy; CPS = Cognitive Performance Scale; CHESS = Changes in Health, End-Stage Disease and Signs and Symptoms; DRS = Depression Rating Scale; MAPLe = Method for Assigning Priority Levels

[1)] from mild to unberable pain

**p*<0,05

***p*<0,001

5.2.4 Predictors of caregiver distress in home care settings

Table 5 displays the results of the multiple logistic regression models designed to identify the predictors of caregiver distress, highlighting differences across the six countries. Caregivers living with home care clients were more likely to experience distress, with significant associations observed in Finland, Germany, and the Netherlands. Factors related to the cognitive and physical health of home care clients, such as scores of ≥3 on the CPS, DRS and CHESS scales, and the presence of bladder incontinence, were linked to higher prevalence of caregiver distress. However, the significance of these associations varied by country. Recent hospital admissions were associated with higher rates of caregiver distress across all countries; however, this relationship was statistically significant only in Iceland. Additionally, the duration of formal care was a significant predictor of caregiver distress in Finland, Iceland, and the Netherlands, but the ORs were relatively low (ranging from 1.06 in the Netherlands to 1.10 in Finland). In all participating countries, if the care recipient was female, the likelihood of caregiver distress was lower. Moreover, in Iceland, Finland, and Germany, caregiver distress was lower when the care recipient engaged in at least 2 hours of physical activity in the 3 days before the evaluation.

Table 5. Multiple logistic regression analysis of risk factors for caregiver distress

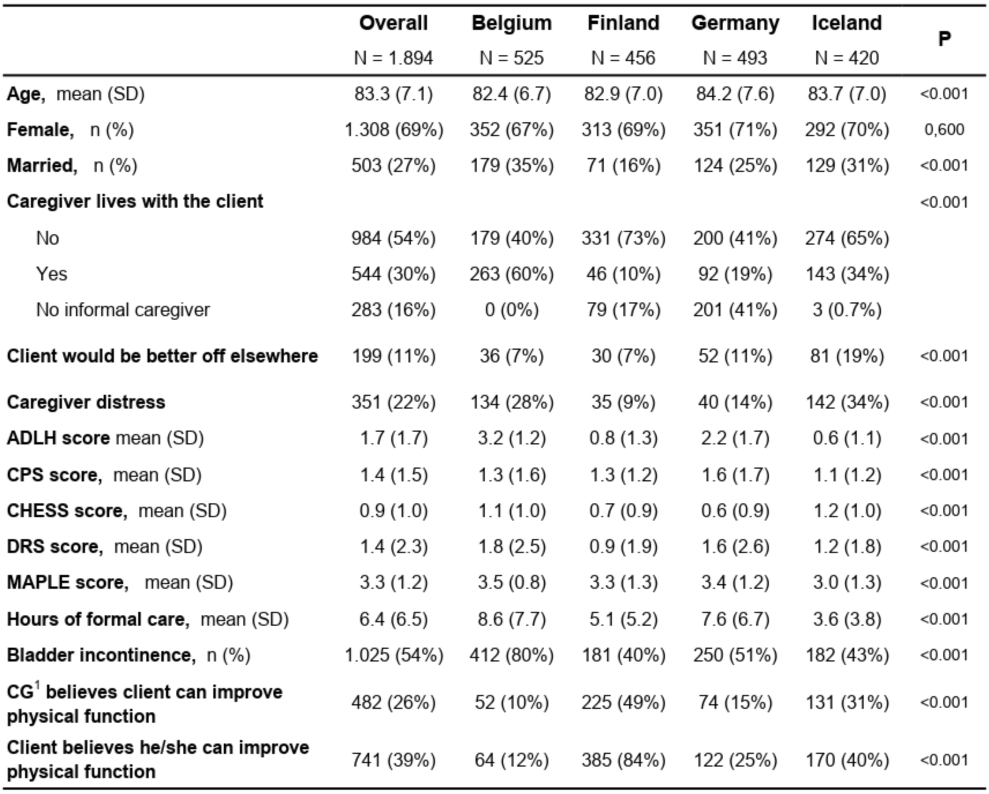
	Belgium		Finland		Germany		Iceland		Italy		the Netherlands		All Countries	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
	(n=482)		(n=379)		(n=292)		(n=417)		(n=496)		(n=491)		(n=2453)	
Aged of the client	0.96*	[0,92 – 1,00]	1,01	[0,95 – 1,07]	1,00	[0,94 – 1,05]	1,01	[0,97 – 1,04]	1,01	[0,96 – 1,06]	1,00	[0,96 – 1,04]	0,99	[0,97 – 1,01
Client is female	0,77	[0,45 – 1,31]	0,54	[0,23 – 1,31]	0,79	[0,34 – 1,84]	0.46*	[0,27 – 0,79]	0,60	[0,30 – 1,22]	0,73	[0,38 – 1,41]	0.63**	[0,49 – 0,81
Caregiver lives with client	1,29	[0,75 – 2,22]	3.20*	[1,05 – 9,80]	3.97**	[1,75 – 9,01]	1,18	[0,70 – 1,98]	1,34	[0,62 – 2,92]	2.56*	[1,33 – 4,93]	1.65**	[1,27 – 2,14
Client DRS score ≥3	1,56	[0,89 – 2,72]	5.36**	[2,13 – 13,46]	4.09**	[1,76 – 9,49]	3.06**	[1,67 – 5,61]	3.10*	[1,38 – 6,96]	3.11**	[1,65 – 5,86]	2.52**	[1,93 – 3,29
Client CPS score ≥3	1,48	[0,74 – 2,94]	3.63'	[1,18 – 11,19]	1,02	[0,30 – 3,53]	1,81	[0,76 – 4,34]	1,08	[0,40 – 2,65]	0,54	[0,05 – 5,26]	1,42	[0,99 – 2,03
Client Maple score ≥4	1,74	[0,95 – 3,20]	0,84	[0,33 – 2,18]	1,07	[0,36 – 3,16]	2.38*	[1,42 – 3,99]	0,91	[0,38 – 2,21]	0,78	[0,38 – 1,62]	1.40*	[1,06 – 1,85
Client CHESS score ≥3	1,50	[0,65 – 3,49]	3,15	[0,95 – 10,47]	1,05	[0,17 – 6,39]	4.56**	[1,93 – 10,77]	1,02	[0,47 – 2,25]	1,10	[0,46 – 2,67]	1.72*	[1,21 – 2,45
Bladder incontinence	1,67	[0,82 – 3,45]	1,16	[0,49 – 2,79]	1,45	[0,64 – 3,32]	2.12*	[1,29 – 3,48]	1,23	[0,56 – 2,70]	1,22	[0,66 – 2,25]	1.62**	[1,24 – 2,11
Hospital stay last 90 days	1,90	[0,97 – 3,71]	2,06	[0,88 – 4,82]	1,20	[0,42 – 3,41]	2.32*	[1,35 – 4,01]	1,38	[0,69 – 2,75]	1,42	[0,61 – 3,35]	1.71**	[1,29 – 2,27
Hours of formal care1)	0,97	[0,94 – 1,01]	1.10*	[1,02 – 1,18]	0,97	[0,92 – 1,06]	1.07*	[1,01 – 1,14]	1,04	[0,94 – 1,15]	1.06*	[1,01 – 1,12]	1,02	[0,99 – 1,04
Client engaged in ≥2 hr of physical activities in the last 3 days	1,70	[0,82 – 3,52]	0,50	[0,11 – 2,37]	0,42	[0,13 – 1,35]	0.38*	[0,16 – 0,90]	2)	[–]	1,04	[0,55 – 1,96]	0,82	[0,58 – 1,17

5.3 Paper III - Characteristics of home care clients as predictors for nursing home admission: analysis based on interRAI-Home Care data from four European Communities

Table 6 presents the characteristics of home care clients who participated in Study III: a total of 1,894 participants from four countries—Belgium, Finland, Germany, and Iceland. The overall mean age was 83.3 years, with the highest mean age observed in Germany (84.2 years), followed by Iceland (83.7 years). Most participants were female (69%). Only 27% had a partner, with the lowest percentage observed in Finland (16%) and the highest in Belgium (35%). Across the participating countries, 16% of clients did not have an informal caregiver, with significant variation between countries. Caregiver distress was most prevalent in Iceland (34%) and least common in Finland (9%).

Home care clients in Belgium had the highest mean scores on most scales, including ADLH (3.2), DRS (1.8), and MAPLe (3.5), suggesting that their health was worse and they had greater functional decline than those in the other countries. In contrast, participants from Iceland had the lowest mean scores on the functional (ADLH, 0.6), cognitive (CPS, 1.1), and MAPLe scales (3.0), indicating lower care needs. Bladder incontinence was relatively common across all countries, affecting approximately 80% of home care clients in Belgium, 51% in Germany, 43% in Iceland, and 40% in Finland. In the assessment, clients and their caregivers were asked whether they believed that the clients could improve their physical function. In Finland, 49% of caregivers believed that home care clients could improve their physical function, in contrast with only 10% in Belgium

Table 6. Baseline characteristics of home care clients in Study III



	Overall N = 1.894	Belgium N = 525	Finland N = 456	Germany N = 493	Iceland N = 420	P
Age, mean (SD)	83.3 (7.1)	82.4 (6.7)	82.9 (7.0)	84.2 (7.6)	83.7 (7.0)	<0.001
Female, n (%)	1.308 (69%)	352 (67%)	313 (69%)	351 (71%)	292 (70%)	0,600
Married, n (%)	503 (27%)	179 (35%)	71 (16%)	124 (25%)	129 (31%)	<0.001
Caregiver lives with the client						<0.001
No	984 (54%)	179 (40%)	331 (73%)	200 (41%)	274 (65%)	
Yes	544 (30%)	263 (60%)	46 (10%)	92 (19%)	143 (34%)	
No informal caregiver	283 (16%)	0 (0%)	79 (17%)	201 (41%)	3 (0.7%)	
Client would be better off elsewhere	199 (11%)	36 (7%)	30 (7%)	52 (11%)	81 (19%)	<0.001
Caregiver distress	351 (22%)	134 (28%)	35 (9%)	40 (14%)	142 (34%)	<0.001
ADLH score mean (SD)	1.7 (1.7)	3.2 (1.2)	0.8 (1.3)	2.2 (1.7)	0.6 (1.1)	<0.001
CPS score, mean (SD)	1.4 (1.5)	1.3 (1.6)	1.3 (1.2)	1.6 (1.7)	1.1 (1.2)	<0.001
CHESS score, mean (SD)	0.9 (1.0)	1.1 (1.0)	0.7 (0.9)	0.6 (0.9)	1.2 (1.0)	<0.001
DRS score, mean (SD)	1.4 (2.3)	1.8 (2.5)	0.9 (1.9)	1.6 (2.6)	1.2 (1.8)	<0.001
MAPLE score, mean (SD)	3.3 (1.2)	3.5 (0.8)	3.3 (1.3)	3.4 (1.2)	3.0 (1.3)	<0.001
Hours of formal care, mean (SD)	6.4 (6.5)	8.6 (7.7)	5.1 (5.2)	7.6 (6.7)	3.6 (3.8)	<0.001
Bladder incontinence, n (%)	1.025 (54%)	412 (80%)	181 (40%)	250 (51%)	182 (43%)	<0.001
CG[1] believes client can improve physical function	482 (26%)	52 (10%)	225 (49%)	74 (15%)	131 (31%)	<0.001
Client believes he/she can improve physical function	741 (39%)	64 (12%)	385 (84%)	122 (25%)	170 (40%)	<0.001

1) Caregiver

ADLH = Activities of Daily Living Hierarchy Scale; CPS = Cognitive Performance Scale; CHESS = Changes in Health, End-Stage Disease and Signs and Symptoms Scale; DRS = Depression Rating Scale; MAPLe = Method for Assigning Priority Levels Scale; Hours of formal care in average, the last seven days before the evaluation

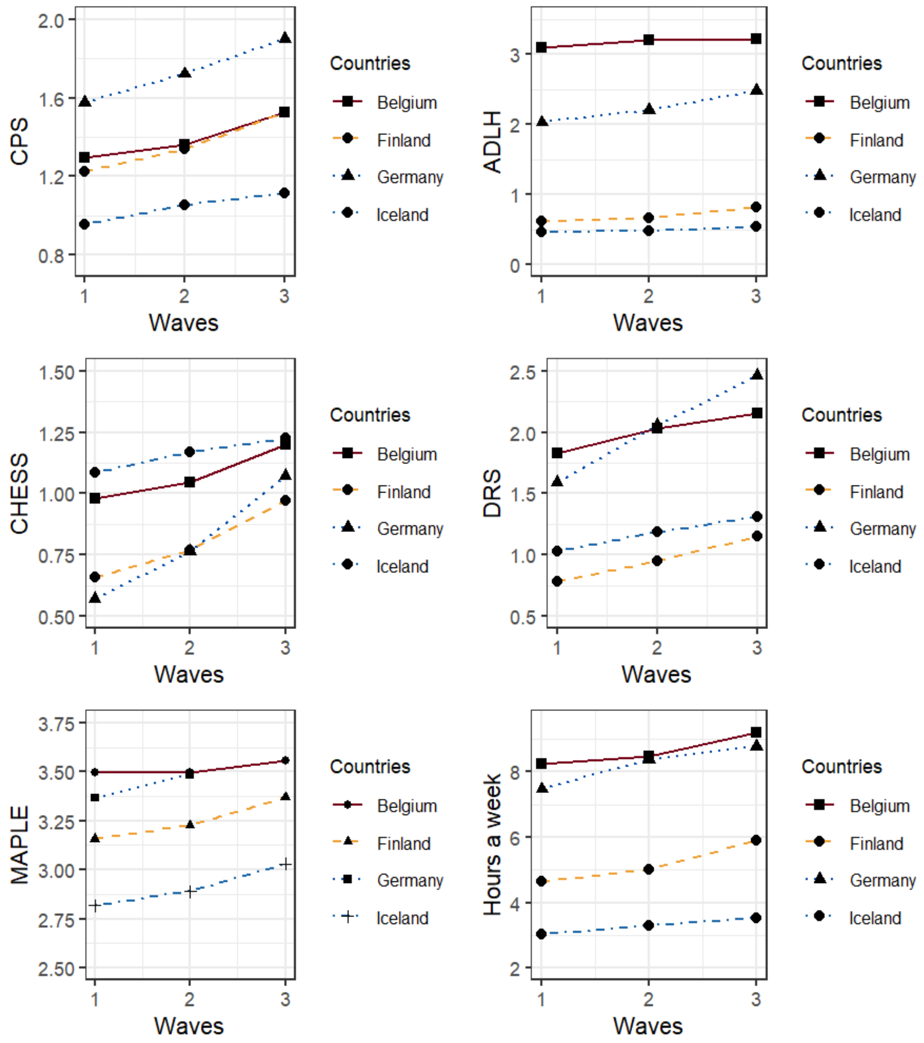
One-way analysis of means (not assuming equal variances);

t-test were conducted for continuous variables: age, ADLH, CPS, CHESS, DRS, MAPLe and hours of formal care

Pearson's Chi-squared test was used for cross-tabs analyses

5.3.1 Changes in health and abilities over one year

Among home care clients who continued living at home at the end of the one-year study period, a general decline in health and functional abilities was observed, as shown in Figure 8. Significant differences were found across countries for scores on all scales (CPS, ADLH, CHESS, DRS, MAPLe) and for duration of formal care, with *p*-values of <0.001 or 0.000 for each scale. Differences across waves were significant for all scales and duration of formal care ($p<0.05$). The interaction between country and wave was statistically significant for the CHESS scores ($p<0.05$), but not for the other variables. Average scores on the cognitive scale (CPS), depressive symptoms scale (DRS), and health instability (CHESS) increased over time, while changes in physical function (ADLH) were relatively small. The average duration of formal care also increased in all countries, with the most notable rise observed in Finland, from 4.9 to 6.0 hours per week. Each variable is presented on its own Y-axis scale in Figure 8 to reflect its specific distribution and scoring range.



Repeated ANOVA

	CPS	ADLH	CHESS	DRS	MAPLe	Hours a week
Countries	<0.001	0,000	<0.001	<0.001	<0.001	<0.001
Waves	<0.001	<0.001	<0.001	<0.001	0,002	0,001
Interaction of countries and waves	0,775	0,061	0,011	0,125	0,605	0,685

Figure 8. Changes in health, ability, and formal care of home care clients continuing to receive home care services: a one-year follow-up.
Comparison between countries and waves (1, baseline; 2, at 6 months; 3, at 12 months)

CPS = Cognitive Performance Scale; ADLH = Activities of Daily Living Hierarchy Scale; CHESS = Changes in Health, End-Stage Disease and Signs and Symptoms Scale; DRS = Depression Rating Scale; MAPLe = Method for Assigning Priority Levels Scale; Hours a week = Hours of formal care in average, the last seven days before the evaluation

5.3.2 Clients discharged from Home Care

Clients were discharged from home care for various reasons. Some had received support for temporary conditions, whereas others regained their independence and no longer required home care. Additionally, some clients were transferred to other parts of the healthcare system, such as health centres. Approximately 12% of the clients moved to nursing homes despite receiving formal assistance, whereas 10% died. During the study year, 30% of participants were discharged from home care. The highest discharge rate was observed in Iceland (approximately 35%), followed by Belgium (33%), and Germany (27%). Finland had the lowest discharge rate (26%). As shown in Figure 9, Iceland had the highest proportion of clients transitioning to a nursing home (18%), followed by Finland (13%), Belgium (12%), and Germany (7%). In Germany, the highest percentage of participants (14%) died during the study period, followed by 11% in Belgium, 10% in Iceland, and 2% in Finland.

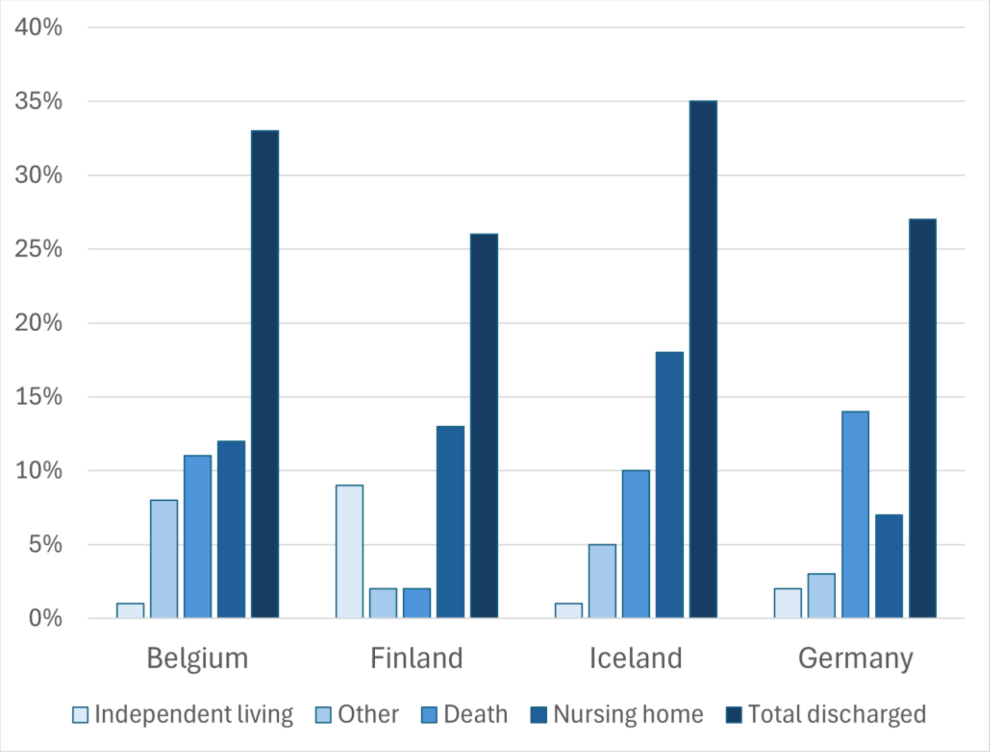


Figure 9. Proportion of home care clients discharged from home care for various reasons during one-year follow-up

5.3.3 Factors associated with home care clients moving to a nursing home

Table 7 presents the sociodemographic and health characteristics of home care clients, stratified by those who continued receiving home care versus those who moved to a nursing home. Predictive factors of nursing home admission varied significantly across the four countries. In Belgium, clients who moved to nursing homes were notably older than those who remained at home (mean age: 84.4 years [5.5] vs. 81.9 years [6.8], $p<0.05$). A similar age difference was observed in Finland (mean age: 84.8 years [5.6] vs. 82.5 years [7.2], $p<0.05$); however, this was not observed in Germany or Iceland. Among those who moved to a nursing home, a higher proportion did not live with a caregiver, except in Iceland (see Table 7 for details).

In Iceland caregiver distress was significantly higher among those caring for clients who moved to nursing homes (58% vs. 25%, $p<0.001$), however, this difference was less pronounced in other countries. A higher proportion of home care clients transitioned to nursing homes when either the client or their caregiver believed the client would be better off living elsewhere. This difference was statistically significant in Belgium (20% vs. 5%, $p<0.001$), Germany (27% vs. 7%, $p<0.001$), and Iceland (35% vs. 15%, $p<0.001$), but not in Finland (7% vs. 5%, $p=0.8$).

In both Finland (1.4 [1.7] vs. 0.6 [1.2], $p<0.05$) and Iceland (0.9 [1.2] vs. 0.5 [1.0], $p<0.001$), physical function—as measured by the ADLH scale—was significantly worse among those who transitioned to nursing homes. Additionally, in Finland (3.5 [1.1] vs. 3.2 [1.4], $p<0.05$) and Iceland (3.6 [1.1] vs. 2.8 [1.4], $p<0.001$), clients who moved to nursing homes had significantly higher MAPLe scores than those who remained at home. Moreover, these clients also received more hours of formal care on average, with a significant difference observed in Finland (6.6 [5.4] vs. 4.6 [4.4], $p<0.05$) and Iceland (5.7 [5.0] vs. 3.0 [3.3], $p<0.001$) (Table 7).

Table 7. Characteristics and health and functional abilities of home care clients who moved to a nursing home and those who continued to receive home care in four countries during 12-month follow-up period

	Overall			Belgium			Finland			Germany			Iceland		
	Home care	**Nursing home**		**Home care**	**Nursing home**		**Home care**	**Nursing home**		**Home care**	**Nursing home**		**Home care**	**Nursing home**	
	N = 1262	**N = 231**	**P**	**N = 355**	**N = 63**	**P**	**N = 324**	**N = 58**	**P**	**N = 310**	**N = 33**	**P**	**N = 273**	**N = 77**	**P**
Age, mean (SD)	82.8 (7.2)	84.1 (6.4)	0.009	81.9 (6.8)	84.4 (5.5)	0.002	82.5 (7.2)	84.8 (5.6)	0.008	83.7 (7.8)	83.4 (6.1)	0.800	83.5 (6.9)	83.5 (7.7)	>0.900
Female, n (%)	886 (70%)	156 (68%)	0.500	243 (68%)	40 (63%)	0.500	224 (69%)	39 (67%)	0.900	220 (71%)	23 (70%)	>0.900	199 (73%)	54 (70%)	0.700
Married	318 (25%)	60 (26%)	0.800	119 (34%)	20 (34%)	>0.900	55 (17%)	7 (12%)	0.500	71 (23%)	7 (21%)	>0.900	73 (27%)	26 (34%)	0.300
Caregiver lives with the client			0.002			0.045			0.800			0.071			0.600
No	661 (55%)	143 (64%)		115 (40%)	30 (56%)		237 (73%)	44 (76%)		123 (40%)	19 (58%)		186 (68%)	50 (65%)	
Yes	340 (28%)	62 (28%)		174 (60%)	24 (44%)		31 (9.6%)	6 (10%)		49 (16%)	6 (18%)		86 (32%)	26 (34%)	
No helper	195 (16%)	17 (7.7%)		0 (0%)	0 (0%)		56 (17%)	8 (14%)		138 (45%)	8 (24%)		1 (0.4%)	1 (1.3%)	
Client would be better off elsewhere	98 (7.8%)	52 (23%)	<0.001	17 (4.9%)	12 (20%)	<0.001	17 (5.2%)	4 (6.9%)	0.800	23 (7.4%)	9 (27%)	<0.001	41 (15%)	27 (35%)	<0.001
Caregiver distress	189 (18%)	69 (33%)	<0.001	81 (25%)	18 (31%)	0.500	19 (7.1%)	4 (8.0%)	>0.900	19 (11%)	3 (12%)	>0.9	70 (26%)	44 (58%)	<0.001
ADLH score	1.6 (1.7)	1.8 (1.6)	0.200	3.1 (1.2)	3.0 (1.1)	0.500	0.6 (1.2)	1.4 (1.7)	0.003	2.0 (1.7)	2.1 (1.6)	0.900	0.5 (1.0)	0.9 (1.2)	0.001
CPS score	1.3 (1.4)	1.6 (1.5)	0.002	1.3 (1.6)	1.6 (1.7)	0.200	1.2 (1.1)	1.5 (1.4)	0.200	1.6 (1.7)	1.7 (1.4)	0.700	1.0 (1.1)	1.6 (1.4)	<0.001
CHESS score	0.8 (0.9)	1.1 (1.1)	<0.001	1.0 (0.9)	1.3 (1.1)	0.023	0.7 (0.9)	0.8 (0.9)	0.400	0.6 (0.8)	0.9 (1.2)	0.120	1.1 (0.9)	1.3 (1.1)	0.063
DRS score	1.3 (2.3)	1.4 (2.1)	0.700	1.8 (2.7)	1.6 (1.9)	0.300	0.8 (1.6)	1.1 (1.5)	0.200	1.6 (2.6)	1.7 (3.3)	0.900	1.0 (1.8)	1.4 (2.1)	0.200
MAPLE score	3.2 (1.2)	3.6 (1.1)	<0.001	3.5 (0.8)	3.6 (0.8)	0.500	3.2 (1.4)	3.5 (1.1)	0.021	3.4 (1.2)	3.4 (1.3)	>0.900	2.8 (1.4)	3.6 (1.1)	<0.001
Hours of formal care[1)]	6.1 (6.0)	6.7 (6.0)	0.200	8.3 (6.7)	9.1 (7.2)	0.400	4.6 (4.4)	6.6 (5.4)	0.013	7.8 (6.8)	4.7 (5.3)	0.004	3.0 (3.3)	5.7 (5.0)	<0.001
Bladder incontinence	653 (52%)	143 (62%)	0.004	274 (78%)	51 (84%)	0.400	113 (35%)	29 (50%)	0.041	153 (49%)	18 (55%)	0.700	113 (41%)	45 (58%)	0.012
CG[2)] **believes client can improve physical function**	348 (28%)	40 (18%)	0.002	37 (11%)	4 (6.8%)	0.500	172 (53%)	18 (31%)	0.003	54 (17%)	3 (9.1%)	0.300	85 (31%)	15 (19%)	0.063
Client believes he/she can improve physical function	515 (41%)	89 (39%)	0.600	47 (13%)	8 (13%)	>0.900	276 (85%)	48 (83%)	0.800	80 (26%)	11 (33%)	0.500	112 (41%)	22 (29%)	0.064

[1)] Hours of formal care = Hours of formal care in average, the last seven days before the evaluation

[2)]Caregiver

ADLH = Activities of Daily Living Hierarchy Scale; CPS = Cognitive Performance Scale; CHESS = Changes in Health, End-Stage Disease and Signs and Symptoms Scale; DRS = Depression Rating Scale; MAPLe = Method for Assigning Priority Levels Scale

t-test were conducted for continuous variables: age, ADLH, CPS, CHESS, DRS, MAPLe and hours of formal care

Pearson's Chi-squared test was used for crosstabs analyses

5.3.4 Factors predicting transition from home care to nursing home

Table 8 presents the multiple logistic regression model predicting the likelihood of home care clients moving to a nursing home. In Belgium (OR = 6.6, 95% CI = 2.6 to 16.4) and Germany (OR = 3.8, 95% CI = 1.2 to 11.4), the odds of moving to a nursing home were higher when either the older individual or their caregiver believed the individual would be better off living elsewhere, with statistically significant results in both countries. In Iceland, caregiver distress emerged as the strongest significant predictor of a client's transition to a nursing home (OR = 3.2, 95% CI = 1.7 to 6.0), whereas a score of ≥3 on the ADLH scale increased this likelihood in Finland (OR = 2.9, 95% CI = 1.3 to 6.5). Furthermore, if the home care clients believed they could improve their physical function, the odds of moving to a nursing home were reduced by 53% in Belgium, 57% in Finland, 52% in Germany, and 35% in Iceland.

Table 8. Multiple logistic regression analysis of risk factors for moving to a nursing home within 12 months

	Overall			Belgium			Finland			Germany			Iceland		
	(n=1227)			(n=364)			(n=318)			(n=197)			(n=348)		
Moved to a nursing home	231 (12%)			63 (12%)			58 (13%)			33 (7%)			77 (18%)		
	OR	**95% CI**	**P**	**OR**	**95% CI**	**P**	**OR**	**95% CI**	**P**	**OR**	**95% CI**	**P**	**OR**	**95% CI**	**P**
Age of the client	1.03	(1.01, 1.05)	0.01	1.07	(1.02, 1.13)	0.01	1.05	(1.00, 1.11)	0.06	0.99	(0.93, 1.05)	0.69	1.01	(0.98, 1.06)	0.48
Client is female	0.87	(0.62, 1.23)	0.42	0.79	(0.42, 1.51)	0.46	0.78	(0.38, 1.63)	0.49	1.06	(0.42, 2.92)	0.90	1.03	(0.56, 1.97)	0.92
Caregiver distress	1.63	(1.13, 2.33)	0.01	1.12	(0.53, 2.23)	0.76	0.67	(0.17, 2.08)	0.52	0.72	(0.14, 2.66)	0.65	3.24	(1.76, 6.00)	0.00
Client would be better off elsewhere	2.88	(1.89, 4.36)	0.00	6.61	(2.66, 16.39)	0.00	0.93	(0.22, 3.04)	0.90	3.79	(1.21, 11.43)	0.02	1.27	(0.62, 2.55)	0.50
Client ADLH score ≥3	0.89	(0.63, 1.26)	0.51	0.6	(0.28, 1.35)	0.20	2.87	(1.25, 6.45)	0.01	1.67	(0.67, 4.22)	0.27	0.83	(0.31, 2.07)	0.69
Hours of formal care[1]	1.03	(1.00, 1.06)	0.04	1.00	(0.96, 1.05)	0.89	1.06	(0.99, 1.13)	0.07	0.95	(0.85, 1.04)	0.35	1.15	(1.06, 1.26)	0.00
Client belives he/she can improve physical function	0.57	(0.37, 0.84)	0.01	0.47	(0.11, 1.45)	0.24	0.43	(0.21, 0.84)	0.01	0.49	(0.07, 1.90)	0.36	0.65	(0.33, 1.24)	0.21

[1] Hours of formal care = Hours of formal care in average, the last seven days before the evaluation

ADLH = Activities of Daily Living Hierarchy Scale

6 Discussion

Governmental policies worldwide emphasize supporting the growing number of older people with care needs to continue living at home. To effectively plan home care services and estimate associated costs, it is crucial for the authorities and home care organizations to understand the characteristics and abilities of home care clients. Identifying risk factors for caregiver distress and nursing home admissions can assist care providers in organizing services that enable older people to continue living at home in the community.

6.1 Older people can continue living in their homes with improved home care services

The findings of this study reveal that, over the decade between the AdHOC and IBenC studies, the physical and cognitive abilities of home care clients in the six participating countries have declined. This trend suggests that older people can remain in their homes for longer when there is an increase in home care services. Similar observations have been reported in Sweden (Sandberg et al., 2019) and Ontario, Canada, where a marked decline in physical and cognitive abilities was noted among home care clients between 2003 and 2014 (Hogeveen et al., 2017). However, home care service hours in Iceland and Finland remain significantly lower than those in countries such as Belgium and Germany, where older people continue to live at home despite greater functional impairment than those in Iceland and Finland. This finding suggests an opportunity to expand public support and enhance the ability of older individuals with similar care needs to remain at home, reinforcing the importance of aging in place.

As stated earlier, government policies have focused on enabling individuals with complex care needs to live in their own homes for extended periods. Many countries have adopted this approach, modifying work processes and enhancing service resources. For example, health authorities in Ontario have prioritized discharging individuals from acute care settings to their homes with appropriate services, rather than admitting them to long-term care institutions. Increased home care resources in Ontario have allowed clients to remain at home longer despite facing more complex health challenges (Hogeveen et al., 2017). In Iceland, efforts to integrate health and social services have enhanced the collaboration between emergency services and primary care (Icelandic Ministry of Health and Social Security, 2003; Icelandic Ministry of Welfare, 2016). Initiatives such as clinical pathways for treating heart failure (Bjornsdottir et al., 2021) and electronic access to hospital health records for home care nurses have improved care coordination. These changes have positively influenced the working conditions for home care nurses, enabling them to support clients with complex health needs in continuing to live at home.

6.2 How well do home care services meet the needs of home care clients?

In study I, half of the clients with the highest care needs—those scoring high on the cognitive (CPS) and ADLH scales—received the most minutes of assistance. However, one-third of these high-need clients received only moderate assistance, and one-fifth of them received minimal support, highlighting a subset of clients whose care needs were not fully met, as shown in Figures 3 and 5. A moderate correlation was observed between ADLH scores and the duration of home care provided, indicating some prioritization of services for those with the greatest needs. Nonetheless, some clients with a relatively lower need for physical assistance received substantial assistance. This discrepancy was explained by severe cognitive impairments that necessitated significant support despite good physical health.

While this study indicates that clients received varying levels of home care service, it could not conclusively determine whether their needs were fully met. Other studies suggest that gaps in home care provision remain. For instance, a study from Cyprus reported that although clients expressed satisfaction with nursing care, they desired more frequent visits and additional psychological support. Some reported that their psychological needs were not addressed even after assessments had been conducted (Kouta et al., 2015). Similarly, a study in Norway showed that the defined care needs were fully met in over 60% of clients for tasks such as wound care, blood glucose monitoring, and dietary support but were met in less than 10% of clients for other needs. The authors emphasized the need for more flexible and proactive nursing resources to preserve functional status and prevent avoidable hospitalizations (Næss, 2017).

Equity in home care provision is a critical issue. The Assessing Needs for Care in European Nations (ANCIEN) project explored long-term care systems in Europe and highlighted disparities in access and service delivery (Mot et al., 2012). In Germany and Belgium, individuals with similar needs had equal access to home care, but those with higher needs did not always receive proportionally more care (Van Eenoo et al., 2016). In Finland and Italy, no system ensured equitable access for individuals with similar levels of need (Mot et al., 2012). Findings of Study I align with these observations, as only half of the home care clients with high scores on the ADLH scale and CPS received substantial home care across the entire sample; however, this percentage varied between countries.

Cross-country variations in home care provision in the participating countries signify differences in allocation criteria, available resources, cultural expectations, and legal frameworks. For example, in Italy, families bear significant moral and legal responsibility for the care of older people, which limits the availably of formal home care (Van Hout et al., 2019). In contrast, countries offering more extensive home care services tend to have clients with greater physical and cognitive impairment, enabling them to remain at home longer.

Another study that used data from the IBenC project found notable discrepancies between the formal care provided and expected care, both within and across countries, which could not be explained by case-mix differences among recipients. This highlights the challenges of ensuring equitable home care based on need (Van Hout et al., 2019). Differences across countries may be attributed to varying allocation criteria and the availability of formal and informal care resources. Additionally, cultural expectations and legal obligations regarding informal care create a diverse balance between formal and informal care (Van Hout et al., 2019).

Study I showed that government policies have had some success in enabling older people with higher dependency levels to continue living at home for longer. Most countries in the study showed increased home care services, except Italy, where services had slightly declined. However, the abilities of home care clients and the duration of care provided varied significantly across countries. Furthermore, this study examined the relationship between the cognitive and physical abilities of home care clients and the hours of care they received. The findings demonstrate that clients with impairment received assistance, but it remains unclear whether this assistance fully met their needs.

6.3 Impact of informal caregiving

Caregivers play a critical role in enabling older people to live at home. Their role and impact have been extensively studied. One important area of focus is caregiver distress, which can undermine the caregiver's ability to provide care and lead to earlier institutionalization of the care recipient. Recognizing and addressing caregiver distress is crucial. Tools such as interRAI-HC can help identify distress, whereas targeted interventions—such as respite care, support groups, and technology-based solutions—can mitigate its effects (Lopez Hartmann et al., 2012; Spiers et al., 2021). Although home care providers are well positioned to detect caregiver distress during visits, their focus often remains solely on the care recipient. Authorities should prioritize custom interventions and resources to address the unique needs of caregivers, ensuring that older people can safely age in place.

Study II examined caregiver distress and its predictors among home care clients' caregivers in six European countries. The prevalence ranged from 9% in Finland to 34% in Iceland, with intermediate levels in Germany (14%), the Netherlands (17%), Italy (22%), and Belgium (28%), (Table 3). Caregiver distress was more prevalent among caregivers of clients experiencing depression, deteriorating health, or increased care needs, particularly when the caregiver lived with the care recipient. For instance, caregiver distress was observed when home care clients exhibited increased levels of depression, as indicated by a score of ≥3 on the DRS scale. These findings are consistent with previous reports (Abey-Nesbit et al., 2021; Riffin et al., 2018; Soldato et al., 2008).

Living with the care recipient, often a spouse, was another significant predictor of caregiver distress, which is consistent with findings from studies conducted in Canada and New Zealand and the AdHOC study (Chan et al., 2021; Pauley et al., 2018; Onder et al., 2009). The greater distress among spousal caregivers may be attributed to the continuous demands of caregiving, which often negatively affect their health outcomes (Penning & Wu, 2015). The results highlighted notable variations in caregiver distress across countries, underscoring the importance of context-specific solutions to better support caregivers.

The prevalence of caregiver distress in Iceland is consistent with findings from New Zealand (39.6%) (Abey-Nesbit et al., 2021) but contrasts with studies from Canada, where caregiver distress was just over 20% in both home care (Pauley et al., 2018) and palliative care settings (Hirdes et al., 2012). A comparison with the AdHOC study, conducted 13 years earlier using the same methodology, revealed a significant increase in caregiver distress, particularly in Iceland (2.6% to 34%) and the Netherlands (2% to 17%). These increases may be influenced by societal changes, such as the participation of more women in the workforce and a shift in generational attitudes toward caregiving (European Commission, 2024). Caregivers in Nordic countries, where formal services are expected to play a significant role, may experience heightened caregiver distress when service levels fall short of expectations.

In Iceland and Finland, paradoxically, a higher number of formal care hours was associated with higher caregiver distress. The mean weekly duration of formal care in Iceland and Finland was 3.6 and 5.1 hours, respectively, in contrast with 7.5 and 8.5 hours in Germany and Belgium, respectively. A potential explanation is that, although they receive care for more time, it is still not sufficient to alleviate the care provided by informal caregivers. Insufficient formal care often forces informal caregivers to assume additional responsibilities, increasing their burden. Conversely, formal care can reduce caregiver distress, as demonstrated by Pauley et al.'s study (2018), who reported that daily nurse visits significantly alleviated caregiver distress.

Furthermore, the results demonstrated that declining health and functional abilities among care recipients can contribute to caregiver distress. Factors such as bladder incontinence and higher CHESS scores, which indicate medical complexity and risk of severe health decline, were significant predictors of caregiver distress in Iceland and Finland. The association between incontinence and caregiver distress was also observed in the pooled data across all countries, underscoring its relevance as consistent and intensive care needs. This finding is supported by previous research identifying incontinence as a major contributor to caregiver distress and a frequent reason for institutionalization. While this study did not differentiate the impact of continence issues by caregiver relationship type, such as spousal versus adult child caregivers, this could be an important area for future research to help tailor interventions more effectively.

In Belgium, Germany, and Iceland, MAPLe scores of ≥4—indicating the need for more intensive home care—were linked to caregiver distress, consistent with previous findings (Abey-Nesbit et al., 2021; Chang & Hirdes, 2015; Hirdes et al., 2012; Pauley et al., 2018). In Iceland, hospital visits in the past 90 days increased the likelihood of caregiver distress, likely because of inadequate post-discharge support. In contrast, Canadian caregivers experienced lower caregiver distress post-hospitalization, as additional formal care was typically provided (Pauley et al., 2018).

Study II identified another factor that seemed to reduce the likelihood of caregiver distress in Iceland, Finland, and Germany: when care recipients had been physically active in the last 3 days. These findings are consistent with previous findings in Canada (Pauley et al., 2018). Iceland's 'Aging is Good' action plan (2023–2027) emphasizes promoting physical, mental, and social well-being to support healthy aging, which may help alleviate caregiver burden (Stjórnarráðið, 2023).

6.4 Predictors of nursing home admission vary across countries

The Study III findings demonstrated that the physical and mental health of home care clients who remained at home after one year had generally worsened, with the extent of formal assistance increasing in all participating countries. This suggests that older people with significant care needs can remain at home longer if they receive enhanced support. Therefore, Study III further investigated how home care clients fared with the aim of identifying the key risk factors associated with nursing home admission.

During the one-year study period, 12% of home care clients moved to nursing homes, with the highest rate observed in Iceland (18%), followed by Finland (13%), Belgium (12%), and Germany (7%). Consistent with previous reports (Carpenter et al., 2004; Sagari et al., 2023; Björkstedt et al., 2023), clients who moved to nursing homes in Finland and Iceland had significantly worse physical functioning than those who remained at home, whereas no significant differences were observed in Belgium or Germany. Bladder incontinence was also a key factor, as a higher proportion of individuals with this condition moved to nursing homes, similar to findings in other studies (Berete et al., 2022; Corrao et al., 2024; de Stampa et al., 2019; Sagari et al., 2023).

Higher MAPLe scores, indicating greater service needs, were associated with nursing home admission in all countries except Germany, where no significant differences were observed. In Iceland and Finland, the association was statistically significant, in line with findings from previous studies (Betini et al., 2017; Björkstedt et al., 2023; Nuutinen et al., 2017; Sørbye et al., 2010). Notably, clients in Belgium and Germany who received more formal assistance were able to remain at home despite greater physical and cognitive impairment. In Germany, those who remained at home received significantly more hours of assistance than those who moved to nursing homes, indicating stronger support from formal care systems.

The strongest predictor of nursing home transfer was the belief of clients or caregivers that the client would be better off living elsewhere, with a statistically significant association observed in Belgium and Germany. This perception, which potentially signifies concerns about isolation, unmet needs, or safety, aligns with findings from earlier Nordic studies (Sørbye et al., 2010). Moreover, caregiver distress strongly predicted nursing home admissions, particularly in Iceland, where this association was significant, consistent with previous findings (Betini et al., 2017; Jamieson et al., 2019).

In contrast with some previous reports (Berete et al., 2022; Corrao et al., 2024; de Stampa et al., 2019), depression did not significantly predict nursing home admission in Study III, which was consistent with the findings reported by Björkstedt et al., (2023). However, caregiver distress emerged as a critical factor, especially in Iceland, where limited formal care hours likely increased caregiver distress, even though home care clients in Iceland are reported to have better health and abilities than those in the other European countries (Kristinsdottir et al., 2021; Van de Roest et al., 2019).

6.5 Tailored interventions to support Aging in place

Delaying or reducing the risk of a nursing home transition requires tailored, multifaceted interventions. Research shows that integrated care approaches—such as high-quality primary care, intensive home support, respite services, and short-stay options—are more effective than single-focus strategies (Luker et al., 2019). Standardized tools, such as the interRAI-HC, enable healthcare professionals to assess clients' risk factors and create individualized care plans, supporting older people to remain living at home longer.

These findings emphasize the need for targeted interventions that address both the physical and emotional needs of home care clients and their caregivers to support aging in place, that is continued living at home. The variability in predictors across countries highlights the importance of adapting interventions to local contexts. Public services must align with the preferences of older people to remain at home as long as possible, prioritizing efforts to delay or prevent a transition to institutional care.

6.6 Expanding understanding of home care needs

While this thesis has primarily focused on traditional indicators of need—such as physical, cognitive, and functional status the findings also highlight the importance of considering broader and more holistic care needs for ensuring comprehensive and person-centred support. For instance, caregiver distress emerged as a major issue, particularly in Iceland, and was identified as key predictor of nursing home admission. This underlines the need to assess not only the clients' physical and cognitive conditions but also their social, emotional, and relational contexts, and to ensure that identified needs in these domains are addressed through appropriate support and intervention.

Recent work by Fowokan et al. (2023) has emphasized this broader view by mapping interRAI-HC assessment items to the My Positive Health framework, a model that defines health across six dimensions: bodily functions, daily functioning, mental well-being, quality of life, participation, and meaningfulness. Their study found that while the interRAI-HC effectively captures many physical and mental health domains, it does not fully address areas such as meaningfulness and social participation, which are essential to well-being among older people.

Building on this, Saari et al., (2024) used interRAI-HC data to identify six client profiles that reflect complex combinations of medical, cognitive, functional, and psychosocial needs rather than relying on isolated diagnoses. Their findings underscore the value of adopting a 'life care' approach, an inclusive, person-centred model of care that matches the diverse and evolving needs of older people living at home.

These insights could inform future care planning and service development in Iceland by encouraging a shift toward more holistic, person-centred care approaches.

6.7 Strengths and limitations

The primary strength of this study lies in its use of the internationally validated and reliable interRAI-HC assessment tool. This tool facilitates meaningful comparisons across countries and timeframes, as it is client centred and based on standardized evaluations by trained assessors. This ensures accuracy and consistency in data collection, facilitating a comprehensive understanding of the needs of home care clients and challenges in delivering equitable and effective services.

Another major strength of this study is its multinational scope, as it was conducted simultaneously in six European countries. This provides a unique opportunity to compare home care services, client characteristics, and outcomes across diverse healthcare systems and cultural contexts. The simultaneous data collection ensures consistency in methodology and timing, reducing potential biases related to temporal or systemic variations, and offers valuable insights into the similarities and differences in home care provision across Europe.

Additionally, the study included a one-year follow-up period, which facilitated the monitoring of outcomes over time, for example, whether clients remained in home care, transitioned to nursing homes, or experienced other significant changes.

Despite these strengths, the study has several limitations. Home care organizations in the participating countries were selected on the basis of the diversity of their location, size, management, and form of payment. Thus, the selection reflected various of care practices rather than being representative of a country. Furthermore, explaining differences between countries is challenging, as cultural and organizational variables were not accessible for inclusion in the study. Generalization is limited to the individuals who met the selection criteria.

The baseline data were collected simultaneously for each participant, except in Italy, where baseline data were documented retrospectively 6 months later. Thus, disability levels at baseline may have been overestimated. In the Netherlands, cognitive impairment was extremely low, likely because one of the main reasons for refusal during the recruitment process was cognitive impairment.

In this study, it was only possible to examine the duration of formal services, as the data did not allow for an analysis of the content or composition of the services provided.

In Study II, limited information was available about caregiver characteristics, which may be critical for understanding the association between caregiver distress and clients' outcomes.

6.8 Implication for practice

This thesis has contributed new knowledge on home care clients and their caregivers in six European countries and has shed light on how services are delivered and evolve over time. It provides a foundation for improving home care practices, particularly in Iceland, in line with the initial goal of supporting older people to live at home longer despite declining health or function. At the same time, the studies have raised new questions that point toward future research and development priorities.

The results revealed important cross-national differences in client needs, formal service use, and caregiver distress. Iceland stood out for having the highest rate of caregiver distress, a factor also identified as a key predictor of nursing home admission. These findings strongly suggest that caregiver support must become a more explicit focus of home care policy and service planning in Iceland.

A key implication of these findings is the importance of using a comprehensive assessment tool in home care to evaluate not only the health status of clients but also the risks and warning signs that may signal caregiver distress or predict institutionalization. When signs such as depression, bladder incontinence, or recent hospital discharge are present, it may be necessary to adjust the care plan to meet the client’s changing needs. Services that were appropriate at the time of initial assessment may no longer be sufficient. It is also essential to consider whether the client lives with an informal caregiver, as co-residency is often associated with increased caregiver burden and may indicate a need for additional support.

By addressing the factors found to predict caregiver distress, there may be potential to reduce its prevalence. For example, maintaining the client’s physical activity and mobility is important, as this was associated with a lower likelihood of caregiver distress. Likewise, engaging with informal caregivers about the client’s care situation—particularly when caregivers express the belief that the client would be better off in a nursing home—can provide insight into caregiver burden and help prevent premature institutionalization.

Caregiver distress was the strongest predictor of nursing home admission in Iceland. Reducing caregiver distress should therefore be a top priority in the delivery of home care services. Structured conversations with caregivers about the client's needs and living conditions—at home versus in a nursing home—are critical, especially since this belief (that the client would be better off elsewhere) was one of the key predictors of institutionalization. This attitude may also reflect the emotional and physical strain placed on caregivers. Interventions addressing contributing factors such as bladder incontinence, which was more common among those who transitioned to a nursing home, are especially important. Moreover, supporting home care clients to access rehabilitation services and maintain hope for improvement is vital, as clients who believed they could improve their physical function were significantly less likely to be admitted to a nursing home.

6.9 Future research

Building on the findings of this thesis, several areas for future research should be prioritized to strengthen the evidence base for home care development in Iceland and other comparable contexts.

Caregiver support: There is a clear need for interventions that support informal caregivers. Ongoing research, where my supervisor and I are participating in, using the interRAI Self-Report of Carer Needs (SCaN) assessment will provide valuable insight into caregiver experiences, well-being, and unmet needs. These findings should be used to inform the development of structured support services for family direct services to relieve them of some of the burden of caregiving.

Evaluate service changes: Since the start of this doctoral project, notable changes have been introduced in Icelandic home care services, including the implementation of reablement programs and increased involvement of other professionals such as occupational therapists, nutritionists, doctors, pharmacists, and in some cases social workers. Therefore, it would be valuable to conduct targeted studies in settings where home care services have recently been expanded. Given the significant differences in client profiles observed in this research and the ongoing developments in Icelandic home care, it is particularly important to repeat a similar study using the interRAI-HC assessment. Such research could determine whether current home care clients present with different health, cognitive, and functional profiles compared to those identified in earlier studies. This would help determine whether policy and staffing changes have enabled clients with higher needs to remain at home longer. Such a study could also investigate how changes in the composition and roles of home care teams may be influencing client outcomes and care delivery models.

Tailor services to client groups: There is a need to develop, and test differentiated models of home care that are adapted to specific client groups, such as those with cognitive decline, severe functional limitations, or high personal care needs. In particular, individuals with severe cognitive impairment may require a different type of support than the general home care population. Traditionally, home care services have not been designed to provide specialized assistance for this group, highlighting the importance of identifying and evaluating their needs separately. Experimental or quasi-experimental studies comparing different types or levels of home care could offer valuable insights into best practices for resource allocation and care planning.

Strengthening the role of nurses: As the complexity of home care increases, the coordinating and leadership role of nurses becomes even more essential. Future research should explore how home care nurses experience this evolving role, how well they are supported in practice, and what educational or systemic changes may be needed to enhance their capacity for care management and interdisciplinary coordination.

Define and measure quality: Finally, further work is needed to develop or adapt tools and indicators for defining and assessing high-quality home care services in the Icelandic context. These should reflect both client- and caregiver-centered outcomes, with an emphasis on continuity of care, responsiveness to need, and integration of services.

This doctoral research provides a foundation for both practical improvements and further inquiry into how home care services can best support older people to age in place. Future research should continue to build on these findings, with particular emphasis on caregiver support, service evaluation, and strengthening professional roles to ensure the delivery of effective, person-centred, and sustainable care in the community.

7 Conclusion

This thesis highlights the complexities and challenges of supporting older people to continue living in their own homes, a goal central to many government policies. The findings indicate that while progress has been made, significant gaps remain in home care provision and caregiver support. Over the past decade, the physical and cognitive abilities of home care clients have declined, necessitating an increase in formal care services. However, despite these efforts, only half of the clients with the greatest care needs received substantial assistance, underscoring the need for a closer examination of service allocation to ensure equity and effectiveness.

Moreover, the study investigated the prevalence of caregiver distress in several European countries and identified its key predictors, including depression among care recipients, declining health, significant care needs, and recent hospital stays. These insights can guide healthcare professionals and policymakers in developing targeted interventions to alleviate caregiver burden and improve outcomes for both caregivers and care recipients. The interRAI-HC assessment tool emerges as a valuable resource for identifying caregiver distress and ensuring that informal caregivers receive the guidance and support they need. However, addressing caregiver distress requires not only diagnostic tools but also the establishment of robust resources within the care system to provide meaningful relief.

Additionally, this research highlights the importance of understanding factors that predict the transitions from home care to nursing homes. By identifying these predictors, nurses, healthcare professionals, and policymakers can design proactive and tailored care strategies to help older people maintain their independence for as long as possible, and facilitate a transition to institutional care when necessary.

In future, a comprehensive and flexible approach to home care is essential. Home care services must play a proactive role in preventing health decline, maintaining the functional abilities needed for older people to continue living at home, and addressing the growing demands of an aging population with fewer available caregivers. Future research should focus on optimizing service allocation, exploring unmet needs, and developing interventions that support both care recipients and caregivers. Ultimately, ensuring equitable, personalized, and effective home care services will be key to enabling older people to age with dignity and autonomy in their own homes.

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Paper I

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RESEARCH

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Changes in home care clients' characteristics and home care in five European countries from 2001 to 2014: comparison based on InterRAI - Home Care data

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Abstract

Background: Policymakers advocate extended residence in private homes as people age, rather than relocation to long-term care facilities. Consequently, it is expected that older people living in their own homes will be frailer and have more complex health problems over time. Therefore, community care for aging people is becoming increasingly important to facilitate prevention of decline in physical and cognitive abilities and unnecessary hospital admission and transfer to a nursing home. The aim of this study was to examine changes in the characteristic of home care clients and home care provided in five European countries between 2001 and 2014 and to explore whether home care clients who are most in need of care receive the care required.

Methods: This descriptive study used data from two European research projects, Aged in Home Care (AdHOC; 2001–2002) and Identifying best practices for care-dependent elderly by Benchmarking Costs and outcomes of Community Care (IBenC; 2014–2016). In both projects, the InterRAI-Home Care assessment tool was used to assess a random sample of home care clients 65 years and older in five European countries. These data facilitate a comparison of physical and cognitive health and the provided home care between countries and study periods.

Results: In most participating countries, both cognitive (measured on the Cognitive Performance Scale) and functional ability (measured on the Activities of Daily Living Hierarchy scale) of home care clients deteriorated over a 10-year period. Home care provided increased between the studies. Home care clients who scored high on the physical and cognitive scales also received home care for a significantly higher duration than those who scored low.

Conclusion: Older people in several European countries remain living in their own homes despite deteriorating physical and cognitive skills. Home care services to this group have increased. This indicates that the government policy of long-term residence at own home among older people, even in increased frailty, has been realised.

Keywords: Home care, Formal care, Elderly, Health care policy, interRAI-home care, IBenC, AdHOC

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Background

Countries in the Western world have been preparing for demographic aging. In Europe, the proportion of 65 years and older is expected to increase from 16% in 2010 to 27.8% in 2050 [1]. Policymakers in most countries advocate extended residence in private homes as people age, rather than relocation to long-term care facilities. Therefore, community care for aging people is becoming increasingly important as it facilitates postponement of transfer to a nursing home and prevention of unnecessary hospital admissions [2]. This policy has a number of benefits for older people. They have more control over their own lives, and they enjoy increased independence and autonomy. In many cases, older people have established relationships and roles in their community or neighbourhood, and this contributes to their improved well-being. Staying at home also reduces additional health burdens, compared to nursing homes, such as increased infections and antibiotic resistance [3, 4]. Although the elderly may benefit from continued residence at home, such an arrangement also has some drawbacks. Some older people may have unsuitable housing or may feel isolated, while some may need increased assistance or home care services due to their deteriorating health [4].

In many countries, health and social care authorities have developed multifaceted community-based home care services to support older people living independently. This has led to enhanced interest in home care services for the growing population of frail older people living in their own homes. Home care services have been designed to provide specialized treatments and assist with everyday activities that individuals can no longer perform owing to general physical or cognitive impairment, illness, or lack of knowledge and skills. Home care nurses play an important role in such services as they manage long-term health conditions, prevent unnecessary admission to hospitals, and provide clinical leadership in home care [5, 6]. This trend has necessitated improved knowledge and competence among home care staff to address more complex and extensive care needs [7].

In this study, the impact of European health care policy [8] on older people living longer in the community with higher dependency levels was explored. We aimed to investigate whether older people with complex disabilities and care needs remain living in their own homes with the support of home care services. We were also interested in knowing how the services were distributed, i.e., if those in most need received most services. Using data from two studies undertaken in five European countries with a ten-year interval, it was possible to compare older people's status and circumstances, that is, whether they were living independently and receiving formal and informal care. Formal care refers to paid care provided by healthcare and social institutions, whereas informal care refers to unpaid care provided by family, friends, or neighbours [9]. The older people's demographic characteristics, health status, skills, conditions, and needs as well as the assistance they received at the two respective times was examined. We also explored cross-national differences so that countries can learn from each other and adopt new methods to provide home care services. In this study, the focus was on home care; however, it is known that the relationship between formal and informal assistance is often indistinguishable.

The present study was based on findings from two European studies, the Aged in Home Care (AdHOC) project study from 2001 [10] and the Identifying best practices for care-dependent elderly by Benchmarking Costs and outcomes of Community Care (IBenC) study from 2014 [11]. In these studies, home care or community care is defined as 'care provided at home by social and healthcare professionals' and care as 'domestic aid services; personal care; and supportive, technical, and rehabilitative nursing' [12]. In both studies, home care clients were assessed using the interResident Assessment Instrument for home care (interRAI-HC), which is a comprehensive tool designed to provide holistic information on the status of older persons.

The development of the interRAI began by a team of gerontologists in the United States in the late 1980s, following an audit of the activities in nursing homes where the quality of care had been identified as substantially lacking, activities deficient, and their supervision limited [13]. The aim was to develop a tool to obtain a systematic and comprehensive assessment of the health of nursing home residents, which could then be used to monitor changes. The instrument is in two parts: a data set (minimum data set [MDS]) that contains the components of a comprehensive assessment of the older person and outcomes from various scales embedded in the assessment tool such as the client assessment protocols (CAPs), quality indicators, and resource utilization groups (RUGs; which estimates the cost of care). The results provide treatment guidelines and address the main health problems and participants' general condition, indicating what problems exist or may develop. It was anticipated that the results of such an assessment could be used to develop quality standards for institutions.

The interRAI Nursing Home assessment tool was first implemented in nursing homes in the U.S. in the early 1990s [14]. In the following years, new versions of the assessment tool were developed that were related to different sectors within the health service. In 1996, the interRAI Home Care instrument was introduced for use in assessing home care clients. In addition to assessing cognitive and physical skills, the instrument places emphasis on factors related to quality of life and activity of individuals as well as assistance provided by family caregivers [15, 16].

Since the interRAI-HC instrument was used both in the AdHOC and IBenC studies comparison was made possible. Six European countries participated in the IBenC study (2014–2016): Belgium, Finland, Germany, Italy, Iceland, and the Netherlands. In all these countries, long-term residence in private homes has been encouraged in parallel with increasing age. Five of these countries participated both in the AdHOC study (2001–2002) and IBenC study; Belgium participated only in the IBenC study. Although all the participating countries shared a trend towards demographic aging, considerable variations can be observed in population size between the countries and amount of home care provided in the countries. At the time of the IBenC study, the population size varied from 320,000 in Iceland to 80.5 million in Germany [12]. During the AdHOC study, Germany had the largest population, 82 million whereas the population of Iceland was only 286,000 [10]. The proportion of people older than 65 years, varies between the countries. In 2014, it was highest in Italy, with 31.6%, followed by Germany 31.2%, in Finland 27.7%, Belgium 26.4%, and Iceland 18.9% [12]. When the IBenC study was conducted, community care organizations were not-for-profit organizations in most countries, except in Germany, where 63% were for-profit organizations. In the other countries, the number of private for-profit organizations has been growing, which is perceived as a solution to the increasing demand for care. According to the IBenC data, only Iceland and Italy had hardly any private home care organizations [12]. In all participating countries, only a small proportion of the government expenditures on health care was on long-term home care, whereas the largest part was spent on acute care [12]. All participating countries emphasize the importance of integrated care and the importance of enabling older persons to stay at home for as long as possible [8, 12]. In Italian law, the importance of preventing older people's social isolation is emphasised, but the importance of supporting informal caregivers is not mentioned [8].

Access to home care and funding for long-term care health services vary between the participating countries. In the IBenC study, care is mainly funded through public insurance, taxation, and client co-payments. In Germany and the Netherlands, it is provided primarily through obligatory public insurances, whereas in Belgium, funding depends on the type of care. Public insurance mainly funds care provided by nurses, whereas community taxation funds family care. In Finland, Iceland, and Italy, long-term care health services are mostly funded through national or municipal taxes [8]. Accessibility to home care varies and depends on the availability of care providers, reimbursement systems, and informal care expectations [15]. In Germany and Italy, access to home care is considerably lower than that in the Netherlands [15]. In countries where accessibility to home care is high, home care clients with relatively low dependency constitute the highest proportion of home care recipients, as observed in the Netherlands, Belgium, Finland, Italy, and Germany. Data for Iceland were not available [8, 15, 16].

The present study aimed to examine whether the characteristics of home care clients and the provision of home care in five European countries have undergone changes over the decade and to examine whether services offered met needs meaning that those in most need received most assistance. It was assumed that if the older persons had become frailer, had less functional ability, and required more complex treatments, they would have received more home care to remain living at home. It was also considered important that those who are deemed most in need of assistance receive the most care, more than those who are more self-reliant.

Methods

In this descriptive study, data from two multi-national studies—the IBenC and AdHOC studies—were used. The AdHOC study results were obtained from published peer-reviewed articles [10, 17], and the data for comparison were obtained both from peer-reviewed article [18], and the IBenC database. In the comparison between these two studies and time periods only data from the countries that participated in both studies were used i.e., Finland, Germany, Iceland, Italy, and the Netherlands.

Design and sample

The primary aim of the IBenC project was to identify best practices in home care taking into account both cost and quality [11, 18, 19]. Methods and sample descriptions of the IBenC study have been previously published [11, 18, 19]. In the participating countries, home care organizations in selected areas were invited to participate. Data heterogeneity was required for the development of the benchmark method. Organizations, preferably those using interRAI-HC, were selected based on the variety of their care practices rather than their representativeness. Data were collected simultaneously among three target groups: home care organizations, home care clients, and home care professionals. Only the data from the home care clients were used in the present study. The sample consisted of 2884 home care clients served by 38 home care organizations in the six participating European countries. Data collection followed a prospective longitudinal design with assessments at baseline and 6 and 12 months and was performed between January 2014 and August 2016. For this study, the baseline assessment data were used.

Care recipients are community-dwelling individuals receiving care from enrolled home care organizations. To be eligible for the study, the home care clients were required to be 65 years of age or older and be expected to remain in care for at least 6 months after initiating participation. The following individuals were excluded from the study: clients in the end stage of life, those who received care for a short period of time, those who were going to be institutionalized in the near future, and those with moderate cognitive impairment (Cognitive Performance Scale [CPS] score ≥ 3) without a known informal caregiver or legal representative. It should be emphasized that it was not the general population of older adults that was examined, rather a sample nearly representative of the 'typical users' of community home care services in the participating countries, because only limited number of home care organizations were included, and selection was based on variety in size, care practice, and location. Some selection bias may have been present in the samples from Italy and the Netherlands. In Italy, the baseline data were collected retrospectively for previous 6 months; thus, there was no dropout between the first two points of measurements, and the disability levels may have been overestimated. Cognitive impairment among elderly people receiving home care in the Netherlands was very low, probably because of the recruitment process in two of the three sites where one of the main reasons for refusal was cognitive impairment. Therefore, people with higher levels of cognitive decline were likely underrepresented in the sample from the Netherlands [15]. A limited number of organizations per country were selected based on the diversity in their location, size, care type, management, or payment form. The representativeness of the samples is thus uncertain, except that in Iceland, where the sample fully represents home care clients in the capital area.

The AdHOC study conducted in 2001–2002 focused on describing the aspects of users of home care services, specifically their health, functional status, and other aspects of living conditions [17]. The objective was to link the characteristics of community care recipients, the services they received, and the outcomes of care [10]. Inclusion and exclusion criteria for participating in the AdHOC study were the same as in the IBenC study—community dwelling individuals 65 years and older receiving home care. Further information on methods used in the AdHOC study have been published [10, 17].

Procedure and measurement

All home care recipients participating in the two studies were assessed using the interRAI-HC, which is a comprehensive and structured geriatric instrument [20, 21]. The instrument is used in several countries in health care settings in routine care to support assessment and care planning for vulnerable patients' groups as well as in research studies. The health status of an individual, as well as health problems, are extensively covered, providing an assessment of medical, psychological, social, and functional skills and care needs of dependent elderly living in the community [20–25].

The interRAI Home Care instrument has previously been shown to have inter-rater reliability across countries and settings [26]. The structure and predictive validity of the main scales and risk indicators that are embedded in the interRAI instruments have been tested extensively in multiple national and cross-national studies [27].

The instrument provides a range of data, both circumscribed information about issues such as hearing, vision, and activities of daily living and outcomes from scales that indicate levels of impairment. The scales are specially developed for the instrument and are part of it. In present study the functional status was evaluated using the Activities of Daily Living Hierarchy (ADLH) scale. This incremental scale highlights the loss of skills, both at an early and at a later stage. Fewer points are assigned for skills lost early, such as bathing, and more points are assigned for skills lost later, such as eating. The ADLH scale ranges from 0 (no impairment) to 6 (total dependence). For a score > 3 on the ADLH scale, extensive ADL support is required [28]. Cognitive status was assessed using the Cognitive Performance Scale (CPS), which ranges from 0 to 6. The CPS score indicates the ability to make decisions about everyday life activities and make oneself understood and memory impairment. A score > 3 indicates the presence of moderate to very severe impairment [29].

The care recipients' characteristics such as gender, age, marital status, living alone, functional limitations, and cognitive function are documented. The total time provided by the home care nursing and social services in the previous 7 days was filled out, following instructions in the interRAI-HC manual. The total time for nursing and social services were added to determine the amount of home care time each client received.

Statistical analysis

The results were analysed using descriptive and inferential statistics. Home care clients' characteristics were reported, and comparisons were made between countries as well as between the two study periods. The analysis focused on cognitive and physical skills. The average hours of home care provision were compared between countries and between study periods.

Baseline data from the IBenC study were analysed to examine whether those who were most in need of care received more home care. The home care clients were divided into two groups according to physical and cognitive skills, based on scores on the ADLH scale and CPS, respectively. Those who scored 2 or lower were assigned to one group (low), and those who scored 3 or higher were assigned to another group (high). The cut-off point for needing considerable assistance was set at 3 for both scales [28, 29]. An individual with an ADLH scale score > 3 was considered in need of extensive ADL support, and an individual with a CPS score > 3 was considered to suffer from moderate-to-severe cognitive decline and in need of guidance [28, 29]. The duration of services provided by the home care (in min) in the 7 days before the evaluation were divided into three categories: 1–139 min (little), 140–419 min (moderate), and ≥ 420 min (substantial). The division is based on tradition and experience in home care. Home care for 139 min or less in the last 7 days, meant that clients receive only < 20 min of care per day. Limited assistance can be provided for 20 min per day, so clients who receive such aid are quite self-sufficient. When service is provided for up to 60 min a day, it means that the home care client needs considerable assistance, even twice a day, and probably receives assistance with dressing in the morning and going to bed at night. Clients who need assistance for more than 60 min a day may be significantly disabled and require severe assistance, even several times a day or from two care providers at a time. Cross-tabulation analyses were used to examine whether those most in need of assistance received home care for a longer duration than those in a better physical and cognitive condition. The chi-square test was used to test the significance of the difference between groups.

Correlation tests were performed to examine whether there was a correlation between high scores on the ADLH scale and CPS. It was also examined whether a high score on the ADLH scale or CPS affected the duration of home care received. Pearson's correlation coefficient was used to indicate the strength and direction of the relationship. Analyses were performed using SPSS version 26.0.

Results

Table 1 provides an overview of the sample in the two studies. The number of participants in the IBenC and AdHOC study was 2884 and 1808, respectively (from five countries). The average participant age was significantly ($p < 0,05$) lower in the AdHOC study (81.0 years) than in the IBenC study (83,0 years). The proportion of female participants was higher (p < 0,05) 73,0% in the AdHOC study but 66.9% in the IBenC study; in the latter study, the proportion was similar between countries but was by far the lowest in Italy (57.3%). On average, the majority of participants in both studies lived alone—54.3% in the AdHOC study and 59.4% in the IBenC study—but a great variance was observed between countries, from 16.4% in Italy to 80.9% in Finland in the IBenC study. The differences among the studies were found to be significant ($p < 0.05$).

Regarding home care recipients' physical and cognitive skills, the mean CPS and ADLH scale scores were significantly (p < 0,05) higher in 2014 (IBenC) than in 2001 (AdHOC) (Fig. 1). The CPS score was also significantly ($p < 0{,}05$) higher in 2014 in all countries except the Netherlands, where it was lower; it was also the lowest CPS score (0.6) reported in 2014, whereas the home care clients in Italy had the highest CPS score (2.4). The mean score on the ADLH scale was significantly (p < 0,05) higher in the IBenC study (1.6) than that in the AdHOC study (1.0). In the IBenC study, home care clients in Italy scored the highest both on the physical and cognitive scales (Fig. 1), indicating that they had the highest care needs, whereas home care clients in Iceland and the Netherlands showed the lowest levels of cognitive and functional decline. These findings were consistent with the findings from the AdHOC study.

The duration of home care nursing and social services provided in the previous 7 days was significantly higher ($p < 0{,}05$) in the IBenC study (4.4 h) than in the AdHOC study (2.2 h). The duration of home care provided was the lowest in Italy (1.0 h) and the highest in Belgium (8.5 h) (Fig. 2).

A cross-tabulation analysis of the score on the ADLH scale and duration of home care received (Fig. 3) found a significant relationship ($p < 0.05$) between physical impairment and getting the most assistance from home care. Results indicated that more than half of those who had severe physical impairment received substantial home care, whereas 30 and 18% received moderate and little assistance, respectively. Over 20% of those who did not have severe physical impairment received substantial help. Cross-tabulation analyses performed for each country showed a significant relationship (p < 0.05) between severe physical impairment and substantial home care received in Iceland, Finland, Belgium, and Germany (Fig. 4). In Germany, 88 and 12% of those who scored high on the ADLH scale received substantial and moderate assistance, respectively. In Iceland and Finland, 62% of those who scored high received substantial care, but 24 and 29% received moderate assistance, respectively, and 9 and 14% received little assistance, respectively.

The duration of home care received was significantly higher for home care clients with moderate-to-severe cognitive impairment than for those who scored lower on the CPS ($p < 0.05$), as seen in Fig. 5. Cross-tabulation analysis performed for each country individually (Fig. 6) indicated a significant positive relationship ($p < 0.05$) between the severity of cognitive impairment and duration of assistance from home care in Iceland, Finland, and Germany. Home care clients in Germany received more assistance than home care clients in the other countries

Table 1 Characteristics of the home care clients in AdHOC and IBenC

	Belgium		*Finland*		*Germany*		*Iceland*		*Italy*		*the Netherlands*		*All*		
	AcHOC$^{1)}$	*IBenC*	*AcHOC*$^{2)}$	*IBenC*	*AcHOC*$^{2)}$	*IBenC*	*AcHOC*$^{2)}$	*IBenC*	*AcHOC*$^{2)}$	*IBenC*	*AcHOC*$^{2)}$	*IBenC*	*AcHOC*	*IBenC*	*IBenC*$^{4)}$
Study sample - (n)		(525)	(187)	(456)	(607)	(493)	(405)	(420)	(412)	(499)	(197)	(491)	(1808)	(2884)	(2359)
Female - % (n)		67.0 (352)	82.2 (154)	68.6 (313)	74.7 (453)	71.2 (351)	74.1 (300)	69.5 (292)	63.1 (260)	57.3 (286)	77.3 (152)	68.4 (336)	73.0 (1319)	66.9 (1930)	66.9 (1578)
Living alone - % (n)		48.0 (252)	83.8 (157)	80.9 (369)	62 (375)	73 (359)	68.2 (276)	61.0 (256)	12.8 (53)	16.4 (82)	61.6 (121)	68.8 (338)	54.3 (982)	57.4 (1656)	59.4 (1404)
Age, years - mean (SD)		82.4 (6.7)	81.2 (7.7)	82.7 (7.0)	81.3 (7.9)	84.2 (7.6)	81.4 (7.6)	83.7 (7.0)	80.2 (8.0)	81.8 (7.9)	80.4 (6.7)	82.5 (7.1)	81.0 7.6	83.0 (7.3)	83.0 (7.4)
CPS score - mean (SD)		1.4 (1.6)	0.7 (1.0)	1.3 (1.2)	1.4 (1.8)	1.6 (1.7)	0.6 (1.0)	1.1 (1.2)	2.0 (2.0)	2.4 (2.1)	1.0 (1.1)	0.6 (0.9)	1.1 (1.2)	1.4 (1.6)	1.4 (1.6)
ADLH score - mean (SD)		3.2 (1.2)	0.2 (0.9)	0.8 (1.3)	1.6 (1.8)	2.2 (1.7)	0.2 (0.7)	0.6 (1.1)	2.8 (2.0)	3.8 (1.7)	0.2 (0.8)	0.5 (1.1)	1.0 (0.7)	1.9 (2.0)	1.6 (1.9)
Hours of formal care - mean (SD)$^{3)}$		8.5 (7.8)	2.2 (1.0)	5.1 (5.2)	2.7 (0.8)	7.5 (6.9)	2.2 (0.9)	3.6 (3.8)	1.3 (0.7)	1.0 (2.6)	2.6 (0.9)	4.6 (4.7)	2.2 (0.8)	5.1 (6.1)	4.4 (4.6)

1) Belgium did not participate in AdHOC

2) Data for AdHOC from [8] in the reference list

3) Data for IBenC from [11] in the reference list

4) IBenC without Belgium

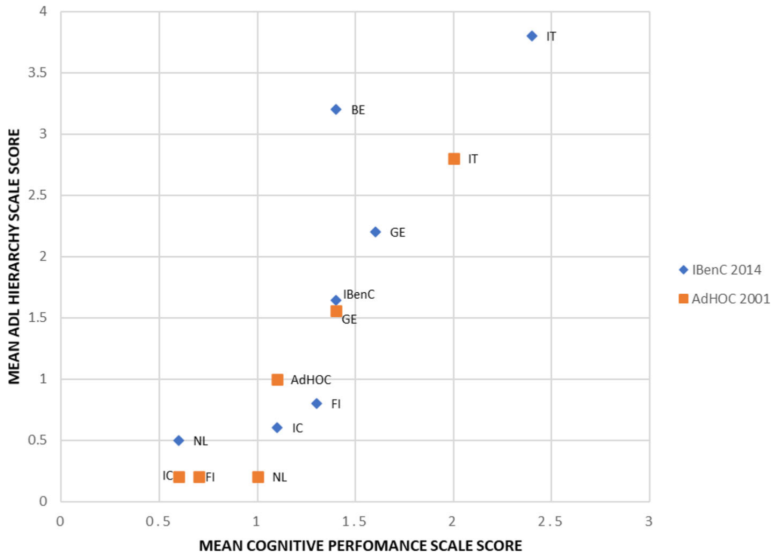

Fig. 1 Relationship between mean Cognitive Performance Scale score and mean ADL Hierarchy scale score by country in the AdHOC □ and IBenC ◊ samples. BE = Belgium, FI=Finland, GE = Germany, IC=Iceland, IT = Italy, NL = the Netherlands. AdHOC = mean values in the AdHOC study and IBenC = mean values in the IBenC study. Mean score in AdHOC and IBenC is without Belgium. Chi-square test $p < 0,05$

regardless of whether they had mild or severe cognitive impairment. In Iceland, 30, 46, and 24% of home care clients with severe cognitive impairment received substantial, moderate, and little home care, respectively. In Italy, only 10% of those with severe cognitive decline received substantial home care. The data on the duration of home care received by home care clients in the Netherlands were not analysed as the number of responses was very low.

A significant, moderate positive correlation ($r = 0.447$, $p > 0.05$) was observed between high scores on the ADLH scale and CPS. There was also a significant, weak positive correlation ($r = 0.349$, $p > 0.05$) between a high score on the ADLH scale and receiving substantial home care, but a very weak correlation ($r = 0.154$, $p > 0.05$) was observed between the CPS score and duration of home care received.

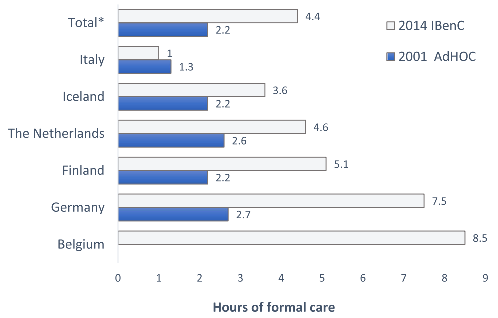

Fig. 2 Hours of home care the last 7 days before evaluation. Difference between countries and studies are significant $p < 0,05$. * Total for Italy, Iceland, the Netherlands, Finland, and Germany. Belgium didn't participate in AdHOC. Chi-square test $p < 0,05$

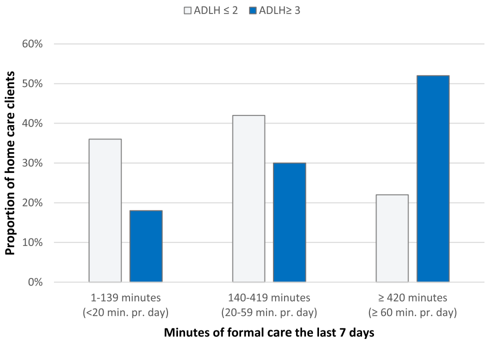

Fig. 3 Relationship between score on ADLH scale and the number of minutes of home care received for the countries together in the IBenC study, the last 7 days before evaluation. Chi-square test $p < 0,05$

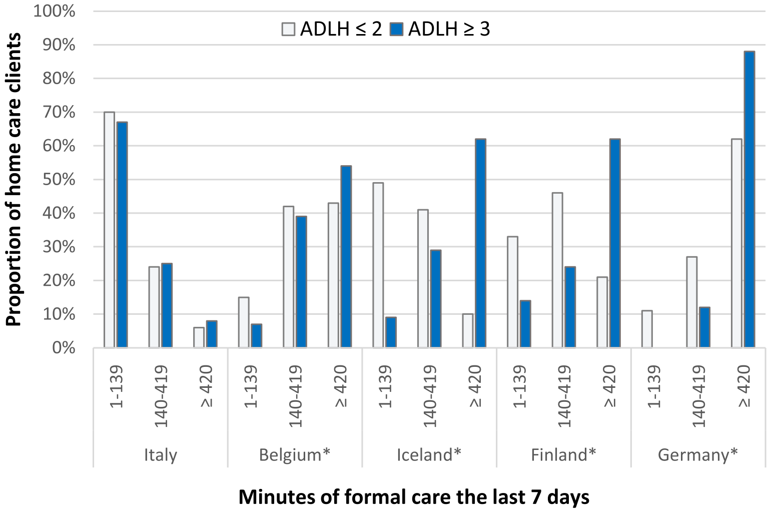

Fig. 4 Relationship between score on ADLH scale and the number of minutes of home care received for each country in the IBenC study, the last 7 days before evaluation. *significant Chi-square test *p* < 0,05

Discussion

The proportion of older people in the society has risen, and governmental policies worldwide have been clear in supporting people with care needs to continue living at home. It is important for governments and home care organizations to be aware of the home care clients' characteristics and skills when they organize home care services and estimate the costs.

The findings of this study indicate that in the 10 years between the AdHOC and IBenC studies, the physical and cognitive skills of home care clients in several European countries have deteriorated, indicating that older people can remain living in their homes for longer if increased home care. Similar findings were reported in Sweden [30] and in Ontario in Canada, where a clear deterioration was observed in home care clients' physical and cognitive abilities between 2003 and 2014 [31].

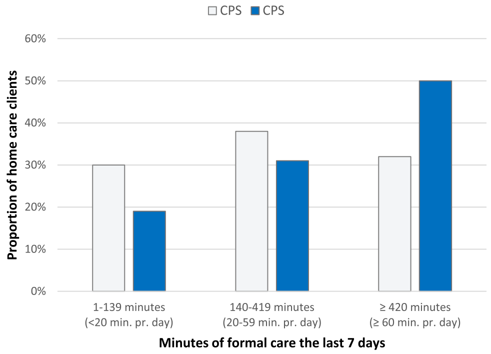

Fig. 5 Relationship between score on CPS scale and the number of minutes of home care received for the countries together in the IBenC study, the last 7 days before evaluation. Chi-square test *p* < 0,05

As stated earlier, the government policy has been to enable people with complex needs to live in their own homes for an extended period. Many countries have followed this policy and changed the emphasis and work processes as well as providing additional and more diverse service resources. Health authorities in the province of Ontario in Canada have emphasized discharging people home from acute care settings before admitting them to long-term care institutions. Increased home care resources in Ontario enable home care clients to live at home longer despite more complex health problems [31]. Another example is Iceland, where the government has been working on integrating health and social services and increased cooperation between emergency services and primary care [32, 33]. Various steps have also been taken to improve collaboration and information sharing between these two services, for example, development of clinical pathways for the treatment of heart failure [34, 35] and opening electronic access to hospital health records for home care nurses. Home care nurses indicate that these measures have changed the working conditions in home care nursing so that frail older people with more complex health problems can live at home.

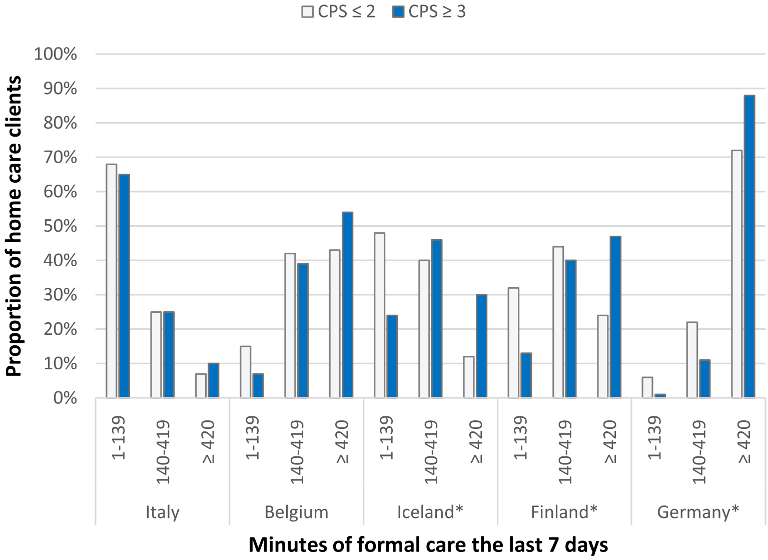

Fig. 6 Relationship between score on CPS scale and the number of minutes of home care received for each country in the IBenC study. *significant Chi-square test *p* < 0,05

In this study, half of those who most needed care, that is, those who scored high on the CPS and the ADLH scale received most minutes of assistance. One-third and one-fifth of those who most needed care received moderate and little service, respectively; thus, there was a group of clients who did not receive the needed home care, as indicated in Figs. 4 and 5. There was a moderate correlation between the score on the ADLH scale and duration of home care received. Therefore, it can be said that the services are prioritised, to a certain extent, for those who are most in need.

A group of home care clients in the study did not have considerable needs but received substantial assistance. Although there was a moderate correlation between high scores on the ADLH scale and CPS, there were some home care clients who were in good physical condition but showed severe cognitive impairment and therefore required substantial assistance. It can be assumed that these home care clients partly explain why one-fifth of those who scored low on the ADLH scale received substantial assistance (Fig. 4) and why just over a third of those who scored low on the CPS received substantial assistance (Fig. 5).

Although home care clients receive moderate-to-substantial service in minutes, it cannot be generalized from these data whether the need for service is fully met. Other studies have shown that home care provided does not always meet the needs. In a study conducted in Cyprus, home care clients reported that they were satisfied with the home care nursing; however, they also wished for more home visits, both from nursing and social care. However, some of them said that they did not receive care and advice regarding their psychological needs; thus, it appears that certain care needs are not met even though assessment for assistance has been conducted [36]. In another study conducted in Norway, the defined care needs of home care clients, as identified by an expert panel, were fulfilled in more than 60% of cases (e.g. clients needing skin and wound care, monitoring of blood glucose in clients with diabetes, and supporting the food intake of those with eating difficulties). Other defined needs were only fulfilled in less than 10% of cases. The authors emphasized that home nursing resources should be more flexible and more proactive to preserve functional status and prevent avoidable hospitalizations [2].

Studies have shown that provision of formal assistance is not equitable. The Assessing Needs for Care in European Nations (ANCIEN) project focused on the future of long-term care (LTC) for the elderly in Europe and addressed questions related to how need, demand, supply, and use of LTC will develop [37]. The project also examined the performance of different systems of LTC. Two types of equity were analysed: equity of revenue raising and equity of resource allocation, further divided into equity of access and equity in levels and mix of services relative to needs. In Germany and Belgium, individuals with the same level of needs were able to access the home care system in the same manner and obtain the same care. However, individuals with higher levels of care needs did not necessarily receive more care although they had more access to the home care system. The ANCIEN project concluded that, in Finland and Italy, there was no system to ensure that people with the same level of need could access the home care system equally [12, 37, 38]; the same can be said about the findings of this study—although home care clients had high scores on the ADLH scale and CPS, not everyone received substantial home care.

Another study that used the data from the IBenC study reported substantial differences between provided and expected formal care both within and across countries that the case-mix differences of the recipients could not explain. It can be concluded that the provision of equal home care services based on need may be challenging [39]. Variation across countries can be expected as allocation criteria and availability of formal or informal resources differ. Cultural expectations and legal requirements related to informal care involvement produce a varied balance between formal and informal care [39].

The results presented here provide an opportunity to map the changes in home care clients' characteristics and home care in several European countries. There is an indication that the government policy has been successful to some degree, as people with higher dependency levels live independently for longer periods. It also appears that governments in the countries included in the studies have adhered to their policy by increasing home care to home care clients, except in Italy, where it has slightly decreased. The findings suggest that home care clients' skills vary among countries, and so does the duration of home care provided by the formal system.

In Iceland, the sample was fully representative of home care clients in the capital area, where over 60% of the country's population lives. The average scores on the ADLH scale and CPS were low but have risen over the 10 years between the two studies. Compared to the other participating countries in the IBenC study, the home care is more limited in Iceland; however, it has improved in the last decade. In those countries where more home care is provided, home care clients have higher physical and cognitive impairments. It appears that increased home care enables people with reduced physical and cognitive abilities to stay longer in their own homes. If the government in Iceland intends to achieve its goal of elderly with complex needs living longer in their own homes, one of the factors required to reach that goal is increasing home care. Italy is an exception because home care is limited and access is not directly related to need because families have an enormous moral and legal responsibility to care for their elderly family members [18].

This study focuses on the relationship between home care clients' cognitive and physical skills and hours of home care provided, and findings indicate that those who need help due to physical and cognitive impairment do receive assistance but not whether such assistance meet their needs. The fact that the analysis only focused on the relationship between clients' physical and cognitive impairment and home care hours provided is a limitation in this study. Other factors, such as diseases, intensity and presence of pain, depression, and assistance from family and friends (i.e. informal care), could also have influenced the time of home care provided to clients. In future research, the interplay of these factors needs to be examined, and interRAI assessments afford many opportunities to do so. The type of home care was not distinguished in this study, but it could be informative to identify the assistance provided by nurses, health care assistants, and domestic care workers. However, the major strength of the present study was the use of the internationally validated and reliable interRAI-HC with trained assessors.

Conclusions

It is concluded that the government policy of supporting older people to live longer in their own homes may have been successful to a certain extent. The physical and cognitive skills of home care clients living at home declined during the past decade. To meet the growing need for assistance, governments have increased their provision of home care to home care clients. In this study, the duration of assistance provided could be determined, but the kind of assistance provided could not be identified. Half of the home care clients who most needed assistance received substantial home care. It is important to examine why the other half only received moderate or little assistance; this factor needs to be investigated more closely, and approaches to provide the required service need to be identified. In future studies, it is also important to further investigate the allocation of services – whether those in most need get the assistance they need – and examine other factors not included in this study. As the number of older adults increases, it is expected that more elderly people will need assistance, and as there will be fewer working hands, it is important services are allotted fairly or provided as needed.

The home care provided must meet individual care needs, be flexible and pro-active to prevent further health decline, and maintain skills for continued residence in private homes.

Abbreviations

AdHOC: AgeD in the Home Care; IBenC: Identifying best practices for care-dependent elderly by Benchmarking Costs and outcomes of Community Care; interRAI-HC: interResident Assessment Instrument for home care;

MDS: Minimum data set; CAPs: Client assessment protocols; RUGs: Resource utilization groups; CPS: Cognitive Performance Scale; ADLH: Activities of Daily Living Hierarchy scale; ANCIEN project: Assessing Needs for Care in European Nations; LTC: Long Term Care

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Authors' contributions
IVK: design of the study, data collection and analysis, drafting and writing the manuscript. KB: supervision and cowriting the manuscript. All authors revised the manuscript and approved the final manuscript.

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Availability of data and materials
The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request and with permission of the IBenC consortium.

Declarations

Ethics approval and consent to participate
Ethical approval for this study was provided by appropriate legal ethical board in Iceland, The National Bioethics Committee in Iceland, No.VSN-13-176-V1.
The authors confirms that all methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication
Not applicable.

Competing interests
PVJ is a member of interRAI and IVK, IH and KB declare no competing interests.

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Publisher's Note

Paper II

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ORIGINAL ARTICLE OPEN ACCESS

Prevalence and Predictors of Caregiver Distress in Six European Communities: Data From the IBenC Study, Using interRAI-Home Care Assessments

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Keywords: ageing | caregiver distress | family caregiver | home care | informal caregiver | interRAI-home care | older people

ABSTRACT

Background: In a changing world where populations are ageing and older people need assistance to live at home, caring for an older relative can be challenging and have various consequences for caregivers.

Methods: In this cross-sectional study, caregiver distress in six European countries—Iceland, Belgium, Finland, Germany, Italy and the Netherlands—was examined and compared. The study aimed to determine the prevalence of distress among caregivers of older people receiving home care in these six countries and identify if factors related to the older person's condition, such as health or function, predict it. The analysis drew on data collected from 2014 to 2016 for the IBenC study (Identifying Best Practices for care-dependent elderly by Benchmarking Costs and Outcomes of Community Care), using the interRAI-Home Care (HC) instrument. A total of 2884 home care clients > 65 years from the six countries participated in the study. Descriptive statistics indicated the characteristics of the sample, and bivariate and multivariate logistic regression models established predictive independent variables for caregiver distress.

Results: The percentage of caregiver distress was highest among Icelandic caregivers (34%). In the other countries, it varied from 9% to 22% and was lowest in Finland. Caregivers of clients with signs of depression, clients who have bladder incontinence or who had stayed in hospital in the last 90 days were more likely to experience caregiver distress. Caregiver distress was more prevalent if a client was at risk of severe health decline and had increased care needs.

Conclusion: Using data from interRAI-HC assessments makes it possible to relate indications of caregiver distress to the characteristics of the older person cared for. Hence, improving their condition might have favourable effects on caregivers. Alertness to caregiver distress is crucial.

1 | Introduction

In recent decades, policymakers have emphasised 'ageing in place' or remaining living in the community despite needing support and care rather than moving to nursing homes. Reflecting the significance of ageing in place is a statement from the OECD (The Organization for Economic Cooperation and Development) suggesting that those needing care should be enabled to continue living in their homes [1]. Governments worldwide have encouraged older people to lead independent lives,

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resulting in an increased number of older people with care needs who remain living in their homes [2, 3] and receiving assistance from formal and informal caregivers [4].

Care for infants and frail older people is essential in all societies; thus, considering what it entails and how it can best be arranged is necessary. Caring for an older family member has become more onerous in recent decades. The caregiver role has become more complex and longer lasting because of medical advances, shorter hospital stays and increased longevity [5]. Informal caregivers usually take on the caregiving role unsolicited and consider themselves ready for the task. Despite their willingness and positivity, they may be unprepared for the physical, emotional, psychological and financial burdens of the caregiving role [6], and they may not possess the appropriate skills to provide care [7]. Caring for an older person with multimorbidity, impaired functional ability and complex care needs can be especially overwhelming and lead to caregiver distress [8–10].

Following the demographic changes described above, many older people are living with more complicated care needs, and the caregiver role has become more complex which has called for rethinking of services provided to frail older people living at home. The United Nations (UN) and the World Health Organization (WHO) developed a strategic plan for healthy ageing, which means creating an environment and opportunities that enable people to be and do what they value throughout their lives and have functional abilities and capabilities that enable them to be and do what they have reason to value. The years 2021–2030 were designated as The UN Decade of Healthy Aging [11].

This plan has influenced the development of services for older people around the world. Governments in various countries have identified service needs and the services provided. As the World Health Organization [11] notes, considering the situation in various countries to realise what must be done to improve care services designed for older people is essential.

Although the idea of ageing in place is usually considered positive, it has meant that much work has been transferred from formal service to older people and their families. Family caregivers, often referred to as informal caregivers since they are unpaid, provide extensive support to older people, making it possible for them to stay at home. In many situations, they may even provide advanced health care and become the older people's case managers and advocates, filling the gaps that often appear in care systems characterised by fragmented services. Informal caregivers are generally family or friends, especially spouses or adult children, as well as children-in-law or neighbours of the care recipients [12]. Most informal caregivers are female; they are wives, daughters and daughters-in-law [13]. It has been estimated that informal caregivers provide 60%–90% of home care [10].

Numerous studies have shown that being an informal caregiver can be stressful and lead to the feeling of burden. The term 'caregiver distress' was coined to describe this situation. Distress has been defined as discomfort, strain or apprehension [14], but in this article, it mainly refers to exhaustion. In studies from New Zealand [8] and Canada [10], predictors of caregiver distress were identified based on results from the older person's interRAI-Home Care (HC) assessments, described below. The results for the two countries were comparable but were not identical. Variables increasing the odds of the onset of caregiver distress included clients′ aggressive behaviour and higher scores on the depression rating scale (DRS), cognitive performance scale (CPS) and the activities of daily living hierarchy scale (ADLH). If the caregiver was a spouse or lived with the client, the likelihood of caregiver distress similarly increased. Being a long-term caregiver and the care recipient being physically inactive or having Alzheimer's or other related dementias also increased distress.

Identifying caregiver distress predictors in the European context, using similar methodologies to those of the previously mentioned studies, contributes to knowledge development in this increasingly important area. Individuals in demanding care roles could become clients with impaired mental, physical and social skills. Therefore, it is important to determine if any characteristics of home care clients enhance caregiver distress. Based on such knowledge, formal care services can be designed to support family caregivers at high risk of caregiver distress.

This study contributes to the literature on older people with multimorbidity living at home and home care services in Europe. It aimed to determine the prevalence of caregiver distress among informal caregivers in six European countries and identify which factors in the client's health, functional status and conditions predict caregiver distress.

2 | Materials and Methods

2.1 | Study Design and Sample

In this descriptive cross-sectional study, data from a European study titled Identifying best practices for care-dependent elderly by Benchmarking Costs and outcomes of Community Care (IBenC) were used. The data were collected in six European countries—Iceland, Belgium, Finland, Germany, Italy and the Netherlands—from 2014 to 2016 [15]. The interRAI-HC assessment was used to collect data from older persons receiving home care services. Methodologies and the sample description of the IBenC study have been previously published [15–17].

The participating home care clients were 65 years or older and remained in care for at least 6 months after initiating participation. Excluded from the study were clients who were at the end stage of life, had planned admittance to a nursing home within 6 months, had received care for a short time and clients who were both diagnosed with moderate or severe cognitive impairment (CPS score ≥ 3) and without a known informal caregiver or legal representative. It was considered important that mentally incompetent persons (scoring ≥ 3 on the CPS scale) had a close relative, legal representative or legal guardian who was competent to provide informed consent on behalf of the home care client and could provide reliable information on clients' care utilisation. Written consent was obtained from participants according to local regulations. Informed consent was not required for clients from home care organisations that utilised interRAI-HC as part of their routine care and were performed for clinical purposes by organisations own staff [15]. The total sample in participating countries consisted of 2884 home care clients served by

38 home care organisations. Data were simultaneously collected from three target groups: home care organisations, home care clients and home care professionals. In the present study, data from home care clients were used. Data collection followed a prospective longitudinal design with interRAI-HC assessments conducted at baseline and again at 6 and 12 months. The analysis presented in this article drew on the data from the baseline assessment.

Home care organisations in the participating countries were selected based on the diversity of their location, size, management or form of payment; thus, the selection was based on various care practices rather than being representative of a country. Therefore, the sample's representativeness remains uncertain, except for Iceland, where the sample, drawn from the entire population in the capital, accurately represents home care clients within that locale.

The baseline data were collected simultaneously for each individual, except in Italy, where baseline data were documented retrospectively 6 months later. Thus, disability levels may have been overestimated at baseline. In the Netherlands, cognitive impairment was very low, likely because one of the main reasons for refusal during the recruitment process was cognitive impairment [15].

2.2 | The interRAI—Home Care Instrument

This study used interRAI-HC, a comprehensive, person-centred, structured geriatric assessment for clients in-home care and community-based settings [18, 19]. This assessment tool is used internationally in health care settings for routine care to support assessment, care planning for vulnerable clients and research studies. It offers a broad overview of a home care client's sociodemographic, health, functional status, resources and service use [19].

The interRAI-HC instrument provides a range of data that are circumscribed information about issues, including hearing, vision and activities of daily living, and outcomes from scales using information from multiple items to calculate a person's risk of a specific event. It provides outcome measures to track clients´ clinical status over time [20]. The ADLH scale is an incremental scale that evaluates functional status and highlights the loss of skills at early and later stages. Fewer points are assigned for early lost skills, such as bathing, and more points are assigned for later lost skills, such as eating. The scores range from 0 (no impairment) to 6 (total dependence) [21]. The CPS scale measures cognitive impairment using items concerning memory impairment, decision-making about daily activities, the ability to be understood and the level of consciousness. The score ranges from 0 to 6, with a score of ≥ 3 indicating the presence of moderate to very severe cognitive impairment [22]. One of the outcomes of the interRAI-HC is the DRS scale, a screening tool for depression. The scale uses several items relating to mood, such as making negative statements, persistent anger with self or others and repetitive anxious behaviours. The score ranges from 0 to 14, with higher scores indicating an increased risk of depression [23]. The Changes in Health, End-Stage Disease and Signs and Symptoms Scale (CHESS) identifies care recipients with higher levels of medical complexity who are at risk of severe health decline. Items included in the scale are health conditions, end-stage disease, nutritional issues and changes in decision-making and ADL status. Scores on the CHESS scale range from 0 (no health instability) to 5 (very high health instability) [24]. The PAIN scale reports the presence and intensity of pain and ranges from 0 to 4, with higher scores representing greater pain. The interRAI-HC also includes decision support algorithms, such as the method for assigning priority levels (MAPLe), an algorithm that provides composite measures by combining various factors, such as ADL impairment, cognition, falls, IADL and behaviour. It indicates older peoples' care needs, predicts long-term care placement and may indicate caregiver distress [25].

2.3 | Study Variables

Although the interRAI-HC assessment mostly captures information about older people receiving home care, three items focus on the informal caregiver and have been used to assess caregiver distress [8, 10, 26–28]. The first concerns whether a caregiver can continue caring activities due to declining health; the second reflects the primary caregiver's expressed feelings of distress, anger or depression; and the third allows family and close friends to report feeling overwhelmed by the older people's illnesses. In this study, caregiver distress was identified as present if one or more of these items was recorded as true by the assessor. These three items are closely related, and it is considered important for identifying the reserves of the informal caregiver support system to include all three of them [8, 27–29].

Of the sample, 388 home care clients, constituting 13.5%, reported having no informal caregivers and were thus excluded from the analysis. Those who had informal caregivers were divided into two groups: (1) those with a caregiver who indicated caregiver distress as defined earlier, and (2) those with a caregiver who did not indicate caregiver distress. These two groups were compared on clients' sociodemographic and health characteristics from the interRAI-HC assessment. The selection of variables to test association with caregiver distress was based on previous literature and the researchers' clinical experience. The following variables related to older people being cared for were used: age, gender, marital status, primary caregiver living with the client, physical activity over the previous 3 days and health-related characteristics, such as nutritional difficulties, dyspnoea at rest and bladder or bowel incontinence. Outcomes from the ADLH, CPS, CHESS, DRS, MAPLe and PAIN scales were used for the comparison. The association between caregiver distress and several other factors was also examined, including the older peoples need for telephone assistance, daily monitoring by a home care nurse, hospital admission within the past 90 days, and the average number of hours of formal care received per week. The number of formal care hours was calculated by summing the hours of service provided by home care and social service entities to the client in the 7 days preceding the evaluation.

2.4 | Data Analysis

Descriptive statistics were used to describe the characteristics of the sample, as were the proportion of people with caregiver distress. Cross-tabulation analysis was utilised to assess the prevalence of caregiver distress across various conditions and client characteristics, applying a chi-squared test to evaluate differences between groups with a significance level of $p < 0.05$. T-tests were also conducted to explore the effect of continuous variables like age and hours of formal care on caregiver distress, maintaining the same significance threshold. The primary outcome, distress versus not distressed caregivers, was analysed using bivariate logistic regression to generate odds ratios and 95% confidence intervals. Variables that were statistically significant in any of the countries were considered for inclusion in the multiple logistic regression model. This multiple approach allows for a comprehensive analysis that controls for confounding factors, reveals complex relationships between variables and enhances understanding of the influence on the outcome. In this model, caregiver distress was the dependent variable, and the significant variables hypothesised to influence distress were included as independent variables. SPSS version 28 was used to conduct the analyses.

3 | Results

Table 1 indicates the characteristics of the 2453 study participants who have an informal caregiver and how they were divided among countries. The average age from the six countries was 83.1 years. The majority of participants were female (67.3%), with the lowest percentage in Italy (57.5%) and the highest in the Netherlands (71.3%) and Finland (71.2%).

Just over a third (33.9%) of the participants were married, while more than half (53%) lived alone, ranging from 16.3% in Italy to 78.1% in Finland. About 41.2% of caregivers lived with the clients, 12.1% in Finland and 67.7% in Italy. In 60.7% of cases, the caregiver was a child or child-in-law of the client; spouses accounted for 25.8% and 13.5% had other connections. Informal caregivers in Italy provided the most care, averaging about 23 h 3 days preceding the assessment. Conversely, caregivers in Finland provided an average of nearly 6 h, with the average in other countries being around 8 h. The average score on various scales from the outcomes of the interRAI-HC assessment varies between countries. Home care clients in Germany, Belgium and Italy had the highest scores on average on the ADL and cognitive scales, indicating they had the most impaired abilities.

Figure 1 indicates the prevalence of caregiver distress among informal caregivers caring for home care. The highest percentage was in Iceland (34%), and the second highest was in Belgium (28%), followed by Italy (22%), the Netherlands (17%) and Germany (14%) and Finland (9%). Positive responses to each of the three items concerning informal caregivers varied across countries. The highest percentage (32%) for a single item was from Iceland in response to the statement: 'Primary informal helper expresses feelings of distress, anger, or depression'. The highest response rate (16%) to the statement: 'Informal helper(s) is unable to continue in caring activities – e.g., decline in health of helper makes it difficult to continue' was in Belgium, and the statement: 'Family or close friends report feeling overwhelmed by person's illness' had the highest response rate in Iceland and Italy (10%).

The sociodemographic and health characteristics of home care clients, stratified by clients with a distressed caregiver (WDC) or a not-distressed caregiver (NDC) are shown in Table 2. The predictive variables for caregiver distress varied considerably between the six countries. Where caregiver distress was present, a higher percentage of home care clients were married compared to not-distressed caregivers, reaching statistical significance in all of the countries except Finland. Additionally, a higher incidence of caregiver distress was noted when home care clients lived with the caregiver, with this finding being significant in all examined countries except Italy. Similarly, significant distress was observed in Germany, Iceland and the Netherlands when informal caregivers provided at least 10 h of care 3 days preceding the interRAI-HC assessment. The presence of bladder or bowel incontinence in the care recipient as well as scores of three or higher on the ADLH, CPS and DRS scales or four or higher on the MAPLe scale were associated with an increased likelihood of caregiver distress. However, the statistical significance of these associations varied by country (Table 2).

Among informal caregivers with identified caregiver distress, a higher proportion of home care clients had been admitted to a hospital in the last 90 days compared to those without distress, and the difference was significant in Finland, Iceland and Italy. Home care clients received more hours of formal care, on average, when caregiver distress was present compared to when it was not, and this difference was statistically significant in Finland, Iceland, Italy and the Netherlands.

Table 3 presents the multiple logistic regression models predicting caregiver distress, which indicate the differences among the six countries. Caregivers residing with home care clients had a higher likelihood of caregiver distress, with significant associations noted in Finland, Germany and the Netherlands. Factors related to the cognitive and physical health of home care clients, including scores of three or higher on the CPS, DRS and CHESS scales and the presence of bladder incontinence, were associated with increased caregiver distress. However, the significance of these associations varied by country. Recent hospital admissions were associated with a higher incidence of caregiver distress in all countries included in the study; however, this association was statistically significant solely in Iceland. Furthermore, the duration of formal care was a significant predictor of caregiver distress in Finland, Iceland and the Netherlands, but with a low OR (1.06 in the Netherlands to 1.10 in Finland).

If the care recipient was female, the likelihood of caregiver distress decreased in all of the participating countries. In Iceland, Finland and Germany, the likelihood of caregiver distress also decreased when the recipient engaged in at least 2 h of physical activity in the 3 days preceding the evaluation.

4 | Discussion

This study aimed to determine the prevalence of caregiver distress among home care clients in six European countries and identify which aspects of the client's health, function and conditions predict caregiver distress among informal caregivers. The prevalence of caregiver distress was 34% in Iceland (highest), 28%in Belgium (second highest), 22% in Italy, 17% in the

TABLE 1 | Characteristics of home care clients who have an informal caregiver.

	Belgium		Finland		Germany		Iceland		Italy		The Netherlands		All countries	
	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*
Study sample—*n*		482		379		292		417		496		387		2453
Age, years—mean (SD)	82.5	(6.7)	83.5	(6.6)	84.7	(7.0)	83.7	(7.0)	81.9	(7.9)	82.8	(7.2)	83.1	(7.2)
Female	66.8	(320)	71.2	(270)	70.5	(206)	69.8	(291)	57.5	(285)	71.3	(276)	67.3	(1648)
Married	36.6	(172)	17.7	(67)	34.2	(100)	30.7	(128)	45.0	(202)	38.1	(94)	33.9[e]	(763)
Living alone	47.6	(226)	78.1	(296)	61.0	(178)	60.9	(254)	16.3	(81)	67.4	(261)	53.0[f]	(1296)
ICG[a] lives with the client	59.4	(262)	12.1	(46)	31.5	(92)	34.3	(143)	67.7	(336)	29.7	(115)	41.2[g]	(994)
Informal caregiver														
Spouse	30.7	(148)	11.3	(43)	26.7	(78)	26.9	(112)	30.0	(149)	26.9	(104)	25.8	(634)
Child or child-in-law	55.4	(267)	69.9	(265)	59.2	(173)	61.2	(255)	61.9	(307)	57.4	(222)	60.7	(1489)
Other[b]	13.9	(67)	18.7	(71)	14.0	(41)	12.0	(50)	8.1	(40)	15.8	(61)	13.5	(330)
Caregiver distress	27.7	(133)	9.2	(35)	13.7	(40)	34.1	(142)	22.2	(110)	16.8	(65)	21.4	(525)
Informal care provided[c]—mean (SD)	NA		5.9	(13.5)	8.3	(14.0)	8.8	(14.8)	23.2	(17.2)	7.9	(14.2)	11.6	(16.4)
ADLH score—mean (SD)	3.2	(1.2)	0.8	(1.4)	2.2	(1.7)	0.6	(1.1)	3.9	(1.7)	0.5	(1.2)	2.0	(1.9)
CPS score—mean (SD)	1.4	(1.6)	1.4	(1.2)	1.5	(1.7)	1.1	(1.2)	2.4	(2.1)	0.7	(0.9)	1.4	(1.6)
CHESS score—mean (SD)	1.1	(1.0)	0.7	(0.9)	0.6	(0.9)	1.2	(1.0)	1.6	(1.3)	1.3	(1.0)	1.1	(1.1)
DRS score—mean (SD)	1.8	(2.5)	1.0	(1.9)	1.5	(2.7)	1.2	(1.8)	1.3	(2.0)	1.7	(2.2)	1.4	(2.2)
MAPLe score—mean (SD)	3.5	(0.8)	3.3	(1.3)	3.4	(1.1)	3.0	(1.3)	3.7	(0.8)	2.5	(1.4)	3.2	(1.2)
PAIN scale score—mean (SD)	0.8	(0.9)	1.0	(1.0)	0.7	(0.9)	1.0	(1.0)	0.7	(0.9)	1.0	(1.2)	0.9	(1.0)
Hours of formal care[d]—mean (SD)	8.8	(7.7)	5.3	(5.3)	5.8	(5.4)	3.6	(3.8)	1.0	(2.7)	5.0	(4.9)	4.8	(5.8)

Note: Data are presented as percentages and numbers unless otherwise indicated.
Abbreviations: ADLH, activities of daily living hierarchy; CHESS, changes in health, end-stage, disease and signs and symptoms; CPS, cognitive performance scale; DRS, Depression Rating Scale; MAPLe, method for assigning priority levels.
[a] Informal caregiver.
[b] Other = sibling, other relative, friend and neighbor.
[c] Average hours over the last 3 days.
[d] On average last 7 days.
[e] Ratio of 2254 responses.
[f] Ratio of 2446 responses.
[g] Ratio of 2412 responses.

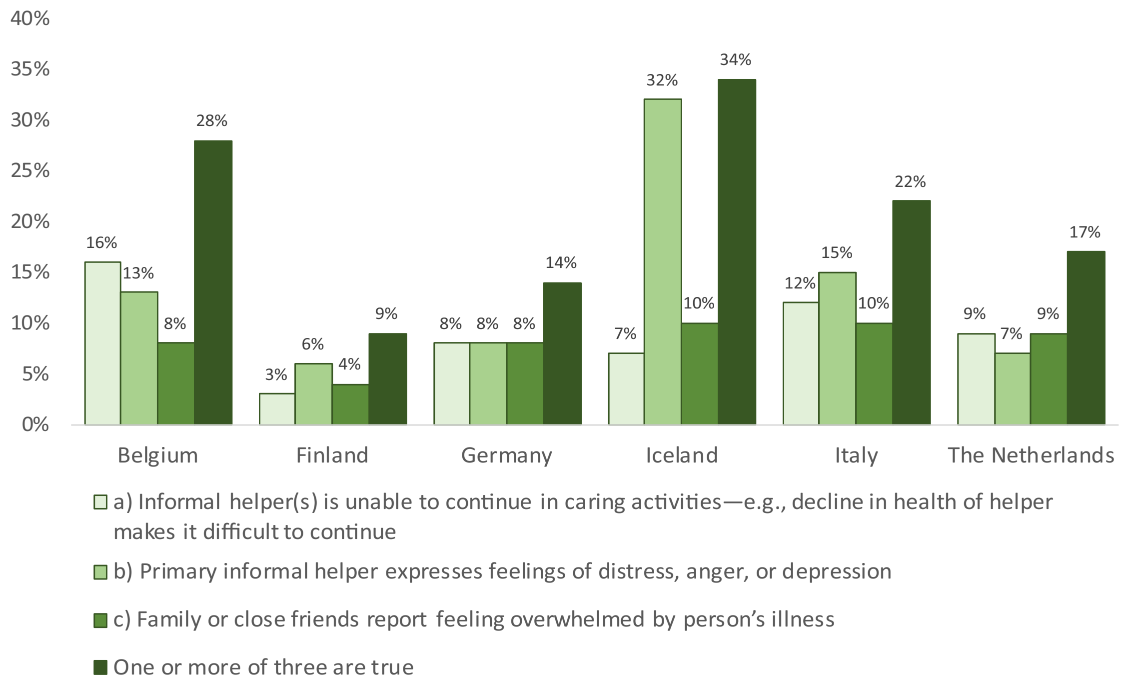

FIGURE 1 | Prevalence of caregiver distress. The rate of responding YES to each statement separately and when YES was to one or more of the three statements.

Netherlands, 14% in Germany and 9% in Finland (lowest). In all six countries, enhanced caregiver distress was noted when care recipients experienced depression and deteriorating health, had increased care needs and a live-in caregiver (Table 3). Results from the different countries studied indicate considerable variations in caregiver distress. The results for Iceland are consistent with findings from New Zealand, where 39.6% of caregivers of home care clients experienced caregiver distress [8]. Similarly, recent studies from Canada have shown a prevalence of caregiver distress of just over 20% for home care [10] and palliative care [27]. The percentages of caregiver distress seen in Finland, Germany and the Netherlands were lower than those published in studies from other countries. In cross-sectional study of caregivers of older relatives with Alzheimer's or other dementias, the rates of caregiver distress were 15.5% in Hong Kong and 13.9% in New Zealand [30]. It should be noted that, unlike the present study, home care clients who have planned admittance to nursing homes in the next 6 months were included in prior research. This fact may attenuate the reported prevalence of distress in the present study, and therefore, comparisons to previous studies should be made with that caveat in mind.

Comparing the results of this study to the results from the AdHOC study, conducted in the same countries 13 years earlier or in 2001–2002, using the same instrument and the same inclusion and exclusion criteria, the rate of caregiver distress has changed. In the AdHOC study, caregiver distress was higher in Germany (15.1%); slightly lower in Finland (5.3%) and Italy (17.7%); and much lower in the Netherlands (2%) and Iceland (2.6%). It should be noted that the item 'Family or close friends report feeling overwhelmed by person's illness' was not included in the AdHOC study [31]. The difference in distress between the two studies in the Netherlands (from 2% to 17%) and especially Iceland is notable, with distress in Iceland increasing to 34%. Such increases indicate that generational attitudes may have changed due to significant social changes. More women are in the labour market and, therefore, face increased demands because they must perform at work, at home and in society [32]. Moreover, the generation that currently has old and even dependent parents may be expected that they want to have more time for themselves and be free to arrange their leisure time independently. The present expectation, especially in Nordic countries, is that formal services will allow older people to live at home longer. Caregivers in these countries assume that the social and health care system will mostly care for their dependent older relatives. Informal caregivers may therefore experience frustration and distress when the services from the formal system do not match that expectation.

This study shows that where the Nordic welfare system is in place in countries such as Iceland and Finland, more hours of formal care were associated with increased caregiver distress. This finding seems contradictory, but the likeliest explanation is that the amount of formal service is insufficient, with only 3.6 h on average weekly in Iceland and 5.1 h in Finland, compared to 7.5 in Germany and 8.5 in Belgium [16]. If an older person has severe needs, this level of formal service may not be enough to ease the burden of care for the informal caregiver, who will, therefore, feel discomfort in the caregiving role. Formal services can decrease caregiver distress, as was seen in Pauley et al.'s

TABLE 2 | Characteristics of home care clients stratified by the presence or absence of caregiver distress.

	Belgium (482)		Finland (379)		Germany (292)		Iceland (417)		Italy (496)		the Netherlands (387)		All (2453)		
	WDC	NDC	WDC	NDC	WDC	NDC	WDC	NDC	WDC	NDC	WDC	NDC	WDC	NDC	Total
	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)
Age—mean (SD)	80.9** (6.4)	83.2 (6.7)	82.7 (6.8)	83.6 (6.6)	83.3 (8.1)	84.9 (6.8)	83.5 (7.2)	83.8 (7.0)	80.3* (8.0)	82.3 (7.8)	81.7 (8.0)	83.1 (7.0)	81.9** (7.4)	83.4 (7.1)	83.1 (7.2)
Female	64.1 (84)	67.7 (235)	60.0 (21)	72.4 (249)	62.5 (25)	71.8 (181)	61.3* (87)	74.2 (204)	45.5* (50)	60.9 (235)	63.1 (41)	73.0 (235)	58.9** (308)	69.5 (1339)	67.3 (1647)
Married	46.9* (61)	32.7 (111)	25.7 (9)	16.9 (58)	65.0** (26)	29.4 (74)	39.4* (56)	26.2 (72)	59.6** (59)	40.9 (143)	55.3* (26)	34.0 (68)	41.8** (237)	29.9 (526)	33.9 (763)
Primary caregiver lives with the HC-client	69.8* (88)	55.2 (174)	25.7* (9)	10.8 (37)	57.5** (23)	27.4 (69)	41.5* (59)	30.5 (84)	73.6 (81)	66.1 (255)	44.6* (29)	26.7 (86)	55.8** (289)	37.2 (705)	41.2 (994)
Informal help ≥ 10 h last 3 days	NA		20.0 (7)	11.3 (39)	47.5** (19)	18.7 (47)	32.4** (46)	17.5 (48)	80.9 (89)	73.0 (284)	35.4** (23)	14.6 (47)	46.8** (184)	29.4 (465)	32.9 (649)
ADLH score ≥ 3	87.6 (113)	83.4 (287)	28.6* (10)	13.4 (46)	67.5* (27)	44.0 (111)	12.7* (18)	6.2 (17)	84.1 (90)	79.4 (296)	10.8 (7)	9.3 (30)	51.2** (265)	41.2 (787)	43.3 (1052)
CPS score ≥ 3	30.1** (37)	14.0 (48)	31.4** (11)	9.6 (33)	32.5 (13)	21.8 (55)	19.0** (27)	4.7 (13)	40.2 (43)	36.5 (136)	3.1 (2)	2.2 (7)	26.0** (133)	15.3 (292)	17.6 (425)
CHESS score ≥ 3	10.2 (12)	7.7 (26)	20.0** (7)	4.1 (14)	5.0 (2)	4.8 (12)	21.1** (30)	3.3 (9)	31.8 (34)	26.0 (97)	16.9 (11)	9.9 (32)	18.9** (96)	10.0 (190)	11.9 (286)
DRS score ≥ 3	37.5** (48)	21.7 (75)	37.1** (13)	11.6 (40)	42.5* (17)	19.4 (49)	28.9** (41)	11.3 (31)	32.7* (35)	19.0 (71)	43.1** (28)	21.7 (70)	35.2** (182)	17.6 (336)	21.3 (518)
Maple score ≥ 4	59.0** (62)	39.5 (120)	57.1 (20)	43.9 (150)	48.7 (19)	36.7 (91)	59.2** (84)	27.3 (75)	60.8 (31)	59.0 (82)	31.1 (19)	22.3 (69)	54.3** (235)	36.3 (587)	40.1 (822)
PAIN scale score ≥ 2[a]	14.6 (19)	20.8 (70)	25.7 (9)	28.5 (98)	20.0 (8)	23.0 (58)	34.5 (49)	32.4 (89)	21.8 (24)	20.7 (80)	33.8 (22)	33.2 (107)	25.1 (131)	26.2 (502)	26.0 (633)
Bladder incontinence	86.3* (113)	77.5 (268)	62,9* (22)	39.6 (127)	65.0* (26)	49.6 (125)	55.6** (79)	36.7 (101)	68.2 (75)	64.8 (250)	52.3 (34)	44.7 (144)	66.7** (349)	52.7 (1015)	55.7 (1364)
Bowel incontinence	62.4** (83)	45.7 (158)	17.1 (6)	14.0 (48)	45.0* (18)	22.6 (57)	14.8* (21)	7.6 (21)	47.3 (52)	46.6 (180)	18.5 (12)	12.7 (41)	36.6** (192)	26.2 (505)	28.4 (697)

(Continues)

TABLE 2 | (Continued)

	Belgium (482)		Finland (379)		Germany (292)		Iceland (417)		Italy (496)		the Netherlands (387)		All (2453)		Total
	WDC	NDC	WDC	NDC	WDC	NDC	WDC	NDC	WDC	NDC	WDC	NDC	WDC	NDC	
	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)
Nutritional problem	34.1* (45)	21.5 (74)	0 (0)	2.9 (10)	20.0* (8)	9.5 (24)	3.5 (5)	3.6 (10)	30.9 (34)	31.1 (120)	7.7 (5)	7.8 (25)	18.5* (97)	13.7 (263)	14.7 (360)
Dyspnoea at rest	5.3 (7)	2.6 (9)	0 (0)	0.6 (2)	2.5 (1)	2.8 (7)	5.6 (8)	2.9 (8)	4.5 (5)	5.4 (21)	10.8 (7)	8.7 (28)	5.4 (28)	3.9 (75)	4.2 (103)
Hospital admission in the last 90 days	16.5 (22)	10.9 (38)	37.1* (13)	21.8 (75)	17.5 (7)	13.1 (33)	34.5** (49)	16.0 (44)	56.4* (62)	45.1 (174)	15.4 (10)	10.6 (34)	31.0** (163)	10.7 (398)	22.9 (561)
≥ 2 h of physical activities in the last 3 days	15.5 (20)	9.5 (33)	5.7 (2)	18.6 (64)	10.0* (4)	27.4 (69)	6.3* (9)	16.7 (46)	0.9 (1)	0.3 (1)	32.3 (21)	34.2 (110)	11.0** (57)	16.9 (323)	15.6 (380)
Client uses phone with assistance	47.4** (63)	27.3 (95)	34.3* (12)	16.0 (55)	32.5* (13)	19.4 (49)	12.0* (17)	4.0 (11)	70.9 (78)	64.5 (249)	7.7 (5)	6.5 (21)	35.8** (188)	24.9 (480)	27.2 (668)
Daily nurse monitoring last 7 days	76.7* (102)	80.5 (280)	5.7 (2)	11.3 (39)	47.5 (19)	61.1 (154)	2.8 (4)	2.9 (8)	2.7 (3)	0.8 (3)	12.3 (8)	5.3 (17)	26.3 (138)	26.0 (501)	26.1 (639)
Hours of formal care - mean (SD)	8.9 (7.1)	8.7 (8.0)	9.2** (8.7)	4.9 (4.7)	6.7 (6.0)	5.7 (5.3)	4.4** (4.2)	3.1 (3.5)	1.5* (3.6)	0.9 (2.3)	6.5* (6.0)	4.7 (4.6)	5.7** (6.3)	4.6 (5.6)	4.8 (5.8)

Note: Chi-square was used for cross-tabs analyses, and *t*-tests were conducted on continuous variables: Age and hours of formal care.

Abbreviations: ADLH, activities of daily living hierarchy; CPS, Cognitive Performance Scale; CHESS, changes in health, end-stage disease and signs and symptoms; DRS, Depression Rating Scale; MAPLe, method for assigning priority levels; NDC, not distressed caregiver; WDC, with distressed caregiver.

[a] From mild to unbearable pain.

*$p < 0.05$.

**$p < 0.001$.

TABLE 3 | Multiple regression analysis of risk factors for caregiver distress.

	Belgium	Finland	Germany	Iceland	Italy	the Netherlands	All Countries
	OR [95% CI]	**OR [95% CI]**	**OR [95% CI]**	**OR [95% CI]**	**OR [95% CI]**	**OR [95% CI]**	**OR [95% CI]**
	(*n* = 482)	**(*n* = 379)**	**(*n* = 292)**	**(*n* = 417)**	**(*n* = 496)**	**(*n* = 491)**	**(*n* = 2453)**
Age of the client	0.96* [0.92–1.00]	1.01 [0.95–1.07]	1.00 [0.94–1.05]	1.01 [0.97–1.04]	1.01 [0.96–1.06]	1.00 [0.96–1.04]	0.99 [0.97–1.01]
Client is female	0.77 [0.45–1.31]	0.54 [0.23–1.31]	0.79 [0.34–1.84]	0.46* [0.27–0.79]	0.60 [0.30–1.22]	0.73 [0.38–1.41]	0.63** [0.49–0.81]
Caregiver lives with client	1.29 [0.75–2.22]	3.20* [1.05–9.80]	3.97** [1.75–9.01]	1.18 [0.70–1.98]	1.34 [0.62–2.92]	2.56* [1.33–4.93]	1.65** [1.27–2.14]
Client DRS score ≥ 3	1.56 [0.89–2.72]	5.36** [2.13–13.46]	4.09** [1.76–9.49]	3.06** [1.67–5.61]	3.10* [1.38–6.96]	3.11** [1.65–5.86]	2.52** [1.93–3.29]
Client CPS score ≥ 3	1.48 [0.74–2.94]	3.63* [1.18–11.19]	1.02 [0.30–3.53]	1.81 [0.76–4.34]	1.08 [0.40–2.65]	0.54 [0.05–5.26]	1.42 [0.99–2.03]
Client Maple score ≥ 4	1.74 [0.95–3.20]	0.84 [0.33–2.18]	1.07 [0.36–3.16]	2.38* [1.42–3.99]	0.91 [0.38–2.21]	0.78 [0.38–1.62]	1.40* [1.06–1.85]
Client CHESS score ≥ 3	1.50 [0.65–3.49]	3.15 [0.95–10.47]	1.05 [0.17–6.39]	4.56** [1.93–10.77]	1.02 [0.47–2.25]	1.10 [0.46–2.67]	1.72* [1.21–2.45]
Bladder incontinence	1.67 [0.82–3.45]	1.16 [0.49–2.79]	1.45 [0.64–3.32]	2.12* [1.29–3.48]	1.23 [0.56–2.70]	1.22 [0.66–2.25]	1.62** [1.24–2.11]
Hospital stay last 90 days	1.90 [0.97–3.71]	2.06 [0.88–4.82]	1.20 [0.42–3.41]	2.32* [1.35–4.01]	1.38 [0.69–2.75]	1.42 [0.61–3.35]	1.71** [1.29–2.27]
Hours of formal care[a]	0.97 [0.94–1.01]	1.10* [1.02–1.18]	0.97 [0.92–1.06]	1.07* [1.01–1.14]	1.04 [0.94–1.15]	1.06* [1.01–1.12]	1.02 [0.99–1.04]
Client engaged in ≥ 2 h of physical activities in the last 3 days	1.70 [0.82–3.52]	0.50 [0.11–2.37]	0.42 [0.13–1.35]	0.38* [0.16–0.90]	[–][b]	1.04 [0.55–1.96]	0.82 [0.58–1.17]

[a] Hours of formal care, on average, in the last 7 days before the evaluation.

[b] Only two responses, statistical analysis is impossible.

*$p < 0.05$.

**$p < 0.001$.

study [10], where it appeared that daily visits from a nurse decreased caregiver distress significantly (OR: 0.75).

In previous studies using the same methodology as this study, except that clients who were planning to move to a nursing home in the next 6 months were not excluded, caregiver distress has been associated with physical, mental, cognitive and social conditions [8, 10, 27, 30]. When a primary caregiver lives with an older person, the odds of caregiver distress in Finland, Germany and the Netherlands were significantly greater. In 80%–90% of cases, this caregiver is a spouse. In Canada [10], New Zealand [30] and in the AdHOC study [31], living with the client also increases the likelihood of caregiver distress. In Vaingankar et al.'s study [33], caregiver burden was measured with the Zarit Burden Interview scale, and being married to the care recipient was a predictive factor (OR: 2.4) for experiencing discomfort in caring. Other studies have shown that spouses who experience caregiver distress have poorer health outcomes [30, 34]. These findings indicate that always being on duty and having to respond to all changes and care needs of one's partner are stressful.

In all participating countries, a higher likelihood of caregiver distress was observed when a home care client scored three or higher on the DRS scale. This increased likelihood has also been observed in other studies [8, 35] and the AdHOC study [36]. Caring for an older person with signs of depression can affect a caregiver's mental well-being. Similarly, physical factors such as bladder incontinence and higher scores on the CHESS scale indicated levels of medical complexity and a risk of a severe decline in health that increased the likelihood of caregiver distress, especially among the Icelandic and Finish caregivers. Scoring 4 or higher on the MAPLe scale, highlighting the need for assistance for home care and predicting long-term care placement were also a predictive item for caregiver distress in Belgium, Germany and Iceland. This corresponds to results of previously published studies [8, 10, 26, 27].

In Iceland, older persons' hospital visits in the last 90 days increased the likelihood of caregiver distress, but one-third of home care clients in Iceland who had caregivers with caregiver distress were admitted to the hospital during that time. Those admitted were likely the frailest, and if they returned home before completing recovery, they might have lost their self-care abilities during the hospital stay. Similarly, if no changes were made to the formal service provided at home after discharge, the family caregiver may have experienced an increased workload. Results from Canada [10] show that hospitalisations in the last 90 days were associated with a lower likelihood of caregiver distress. Hospitalisation was not thought to reduce caregiver distress, but the additional care provided following hospitalisation alleviated it.

Unsurprisingly, the likelihood of caregiver distress reduced in Iceland if an older person had engaged in physical activity for over 2 h in the previous 3 days. This engagement also reduced caregiver distress in Finland and Germany and was consistent with results from Canada [10]. Physical activities require specific physical skills, with mobility reflecting relatively better health. Icelandic health authorities are aware of the importance of physical activity among older people. In a new action plan for services for older people in Iceland (2023–2027) titled *Aging is Good* [37], physical activity is one of the five key elements. The plan highlights actions that promote healthy ageing and require fewer specific services. Facilities for comprehensive mental, physical and social health promotion will be available to increase older people's engagement in physical activities and overall health. With a population of independent older people, families do not need to provide as much care, which could reduce caregiver distress.

Caregivers are important for maintaining older people at home in the community. Therefore, they must feel comfortable in their role and possess the skills and ability to perform it. Caregiver distress can cause informal caregivers to no longer trust themselves in caring for their older family members, meaning that care recipients may not be able to stay at home as long. Awareness of the signs of caregiver distress, for instance, through a comprehensive assessment tool such as interRAI-HC, and providing caregivers with the necessary support to reduce it is crucial. Research has shown that diverse resources, such as respite care, group support and technology-based interventions, can reduce caregiver distress [38, 39]. An understanding and knowledge of the factors that cause or prevent caregiver distress are necessary to improve caregivers' health and well-being. Home care providers are in a superior position during home visits to discuss health and well-being with informal caregivers and note signs of caregiver distress. However, the caregivers are not usually the focus of home care providers' visits. Therefore, signs of caregiver distress are unlikely to be detected.

Authorities need to develop measures to prevent or reduce the likelihood of distress among caregivers. Providing resources that support caregivers is essential. These resources must be tailored to each caregiver. It is equally important to consider ways of preventing caregivers from becoming overly burdened so that older persons can live at home in a safe environment for as long as possible.

The major strength of this study was its use of the internationally validated and reliable interRAI-Home Care assessment tool. This tool allows for comparing results across countries and timeframes because the assessment is based on the client's evaluation. The sample from Iceland represents home care clients in the capital area, where over 60% of the country's population lives, but this is not the case with the other countries. A limitation of the study is the lack of information about caregiver characteristics, which could be necessary for understanding the association with caregiver distress. Moreover, the cross-sectional nature of the data limited its ability to imply causality.

5 | Conclusion

This study indicates the extent of caregiver distress in several European countries and shows how to identify the factors predicting caregiver distress. Accordingly, the findings help professional caregivers gain greater insight into what informal caregivers are experiencing. Assessment outcomes, such as depression or signs of depression, a decline in health, significant service needs and a recent hospital stay, predict caregiver distress. Using the interRAI-Home Care assessment tool can be helpful for home care personnel in their observations.

Knowledge of these factors can help provide and improve support for caregivers. Home care personnel can identify caregiver distress and provide informal caregivers guidance on relieving their stress. Diagnosing caregiver distress is inconsequential without available resources; establishing resources in the service chain is necessary.

Author Contributions

All authors conceptualised the study. I.V.K. conducted data collection, analysed the data, and drafted the manuscript. P.V.J. was a co-investigator in the IBenC study. K.B. supervised the study and co-wrote the manuscript. All authors revised and approved the final manuscript.

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Conflicts of Interest

The authors, Kristin Bjornsdottir and Ingibjorg Hjaltadottir, declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article. The two other authors, Palmi V. Jonsson and Inga V. Kristinsdottir, are part of the interRAI collaborative network of researchers and practitioners.

Data Availability Statement

The data supporting this study's findings are not publicly available due to privacy or ethical restrictions.

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Paper III

Paper III

Characteristics of home care clients as predictors for admission to nursing homes: analysis based on interRAI-Home Care data from four European Communities

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Abstract

Background

The increasing aging population has heightened the demand for effective home care services for older people. However, many healthcare systems struggle to meet this need, leading to growing demand for nursing homes. This study aims to identify factors predicting home care clients' transitions to nursing homes, focusing on their health, abilities, and care conditions.

Methods

This prospective longitudinal study utilized data from the "Identifying best practices for care-dependent elderly by Benchmarking Costs and Outcomes of Community Care (IBenC)" project, conducted in four European countries (Belgium, Finland, Germany, and Iceland) from 2014 to 2016. A total of 1,227 home care clients aged 65 years and older were assessed using the interRAI-Home Care tool. Descriptive statistics, chi-square tests, t-tests, and multiple logistic regression were used to examine factors influencing nursing home admission over one year.

Results

During the study, 12% of home care clients moved to nursing homes, with rates differing across countries. Those admitted were older on average (84.1 years vs. 82.8 years, $p < 0.05$). Among those remaining at home, health and overall ability often declined, as measured by the interRAI scales; Cognitive Performance Scale (CPS), Depression Rating Scale (DRS), Activities of Daily Living Hierarchy (ADLH), and Changes in Health, End-Stage Disease, Signs, and Symptoms (CHESS). Predictors of nursing home admission varied across countries. In Belgium (OR = 6.6, $p < 0.001$) and Germany (OR = 3.8, $p < 0.05$), clients or caregiver believing relocation was the better was a key factor. In Iceland, caregiver distress was the strongest predictor (OR = 3.24, $p < 0.001$), while in Finland, physical ability was the key determinant (OR = 2.87, $p < 0.05$).

Conclusion

Understanding predictors of nursing home transitions helps healthcare professionals develop tailored care plans to support older people in remaining at home. The variation in predictors across countries highlights the need for localized care strategies.

Keywords

Home care, Nursing Home, older people, older individuals, aging, interRAI-home care, IBenC, predictors

Background

The global population is aging. In recent decades, life expectancy at age 65 has increased in the OECD (Organization of Economic Cooperation and Development) countries and is estimated to approach 30% by 2060 [1]. Most older people wish to continue living at home and maintaining their social networks and quality of life, surrounded by a familiar environment and cherished memories [2].

A key objective of the aging policies issued of many countries and international organizations—such as the World Health Organization's (WHO) strategic plan for healthy aging—is to enable older people to live at home for as long as possible and prevent the need for admission to a nursing home. This approach emphasizes creating environments and opportunities that allow individuals to maintain functional abilities and engage in activities they value throughout their lives, even as their care needs increase [3].

To support aging in place, it is essential to provide comprehensive assistance at home, including services for complex needs and, when necessary, round-the-clock care. However, many healthcare systems lack adequate operational implementation of this strategy, funding and sufficient coordination between social and healthcare services, leading to unmet needs among home care clients. In response, several countries have increased in-situ support for older people with escalating care needs at home [4,5], while the WHO has emphasized the importance of integrating home care and social services for older people [6].

There is an increasing emphasis on home care assistance over institutional care across Europe. Health and home care systems in Europe vary significantly, shaped by diverse cultural, economic, and political contexts. The primary funding sources for long-term care health services include public insurance, taxation, and client co-payments. In countries such as Iceland, Finland, and Italy, these services are mainly funded through national or municipal taxation [7]. In contrast, the Netherlands and Germany rely predominantly on mandatory public insurance systems [7]. Belgium employs a mixed funding model, where nursing care is largely financed through public insurance, while family care, including personal and domestic support, is primarily funded by community taxation [7].

A strong home care system is essential to enable older people to maintain living at home despite challenges to their health and abilities [8]. By identifying physical and mental health issues as well as the client's functional abilities, care requirements can be outlined.

Various studies and meta-analyses have been conducted to identify predictors of nursing home admission, employing a range of assessment tools and methodologies [9-12]. Cognitive and functional impairments, dementia, depression, Parkinson's disease, a history of falls and hip fractures, as well as urinary incontinence, have all been identified as predictors of nursing home admission for home care clients [10-16]. Additionally, higher age, lower education levels, living alone, low self-rated health and the use of home care services have also been associated with a higher risk of nursing home admission [15, 17].

With increased public services there has been a notable shift, showing that older people live longer at home despite declining abilities [4]. This suggests further opportunities to enhance home care services, enabling older people to remain at home for longer. Previous research has identified varied predictors of nursing home admission. This study could highlight country-specific predictors which can help refine and improve predictive models across different settings which can lead to more targeted intervention and better allocation of resources based on each country's specific needs. Such knowledge can support the development of more effective services aligned with these identified factors. This study was designed to provide further insight into this complex situation. Data were collected using the interRAI-Home Care (interRAI-HC) assessment, a standardized, comprehensive tool [18].

Findings from studies using the interRAI-HC assessment tool to identify predictors of home care clients' transitions to nursing homes have varied significantly [19-23], indicating the importance of examining local circumstances and individual needs due to the diverse challenges associated with aging. Building on this, the aims of the current study are to 1) examine changes in health, abilities, and conditions among home care clients who remain at home after a one-year period, and 2) identify factors that may predict their admission to nursing homes in four European communities.

Methods

Design and setting

This research draws on data from the IBenC Study (Identifying Best Practices for Care-Dependent Elderly by Benchmarking Costs and Outcomes of Community Care), a prospective longitudinal study conducted between 2014 and 2016 in six European countries: Belgium, Finland, Germany, Iceland, Italy, and the Netherlands. The study utilized the interRAI-Home Care (interRAI-HC) assessment tool. Home care organizations from selected regions in these countries, particularly those already using the interRAI-HC assessment, were invited to participate. To support the goals of the IBenC study, data heterogeneity was essential for developing the benchmarking method. Therefore, home care organizations were selected to represent a variety of care practices, reflecting differences in location, size, management structures, and payment models.

A more detailed description of the methodology and sample in the IBenC study has been published previously [4, 24, 25]. It should be noted that in this study data from Italy were excluded, since the baseline data were documented retrospectively, six months after participants were enrolled in the study [24]. The data from the Netherlands was also excluded, as information on the transfer of home care clients to nursing homes was unavailable.

Participants

Participants consisted of community-dwelling people, 65 years and older, receiving home care services and expected to remain in care for at least six months after initiating participation. The IBenC study is a prospective longitudinal study, and it was considered important that clients were able to participate throughout the one-year study period. Therefore, home care clients were excluded if they met any one of the following criteria: receiving temporary assistance, being in the end stage of life or being likely to move to a nursing home in the near future. If clients who had been diagnosed with moderate or severe cognitive impairment (Cognitive Performance Scale [CPS] score ≥3) did not have an informal caregiver or legal representative, they were excluded. It was considered important that cognitively impaired individuals (scoring ≥3 on the CPS scale) had a close relative, legal representative, or legal guardian who could provide consent on behalf of the home care client and reliable information in relation to the client's care utilization.

The 2,884 home care clients were served by 38 home care organizations in the six countries. The participating organizations were selected based on variation in their care practices, such as diversity of their location, size, management structure, or form of payment. Data from home care clients in Belgium, Finland, Germany and Iceland (n=1,894) were included in the present study. Clients who died during the one-year research period or those whose care needs changed such that they no longer required home care (without moving to a nursing home) and those who did not have complete data (266) were excluded. In the end, 1.227 home care clients participated in the study, as shown in the study flowchart in Figure 1.

Each client was evaluated by trained (research) nurses, using the interRAI-HC assessment three times during the research period, at the beginning (wave 1), after six months (wave 2), and again after 12 months (wave 3).

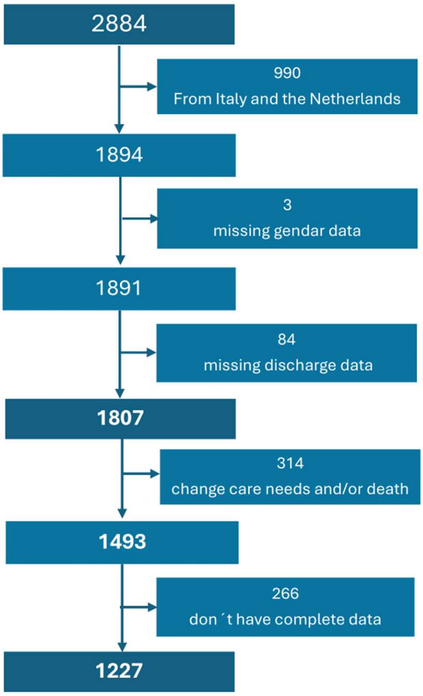


Figure 1 Study flowchart

Measurement

The interRAI-Home Care assessment

In the present study, all the home care clients were assessed using the interRAI-HC assessment. This assessment was designed to evaluate the strengths, needs and preferences of home care clients living in the community [17, 26, 27]. InterRAI-HC is used internationally for routine care in health care settings to support care planning, as well as in research studies. The data gathered provide a broad overview of the physical, mental, social, and cognitive health, functional status, sociodemographic profile, resources, and care needs of dependent older people living in the community [18, 26-28]. Inter-rater reliability across countries has been shown for the interRAI-HC instrument [18, 29, 30].

The interRAI-HC assessment provides comprehensive data on home care clients' health, abilities, and characteristics. This information is gathered through both direct observations and standardized scales derived from multiple assessment items, which collectively delineate levels of impairment [31]. By analyzing these outcomes, a client's status can be tracked over time, facilitating tailored care planning and intervention strategies [31]. To measure physical ability, the Activities of Daily Living Hierarchy (ADLH) scale was used to evaluate functional status. This incremental weighted scale assigns lower scores to early-loss ADLs than late-loss ADLs, i.e., fewer points for activities such as bathing and more points for skills that tend to be lost later on such as eating—the scale ranges from 0 (no impairment) to 6 (total dependence). For a score ≥ 3 on the ADLH scale, extensive ADL support is required [32].

Outcomes from four scales and specific variables were used to assess home care clients' health. The CPS scale measures levels of cognitive performance. The scale ranges from 0 to 6, where a score ≥ 3 indicates the presence of moderate to very severe cognitive impairment [33]. The Depression Rating Scale (DRS) is a screening tool for depression, with scores ranging from 0 to 14, and higher scores indicating an increased risk of depression [34]. The Changes in Health, End-Stage Disease and Signs and Symptoms Scale (CHESS) identifies care recipients with higher levels of medical complexity who are at risk of severe health decline. The scoring of the scale ranges from 0 (no health instability) to 5 (very high health instability) [35].

To assess clients' conditions and circumstances, the MAPLe scale (Method for Assigning Priority Levels algorithm) and hours of formal care provided by the authorities are examined. The MAPLe scale is based on numerous indicators from the interRAI-HC assessment such as ADL ability, cognitive skills, behavioral disorders, wound care, etc. The MAPLe is a decision- support tool that can be used to prioritize clients needing community- or facility-based services and to help plan allocation of resources [36]. The number of formal care hours are calculated by summing the average hours of services provided by home care and social service entities to the client over the seven days preceding the evaluation. In the assessment, the home care client and the informal caregiver are asked whether they believe the client would be better off living elsewhere. Two of the response options—"Yes, in service accommodation" and "Yes, in an institution"—are combined and used in this study as the variable "Client would be better off elsewhere." The third response option is "No." To assess caregiver distress, three items from the instrument focusing on the informal caregiver were combined. If the caregiver answered "yes" to one or more of these items— "Informal helper(s) is unable to continue caring activities"; "Primary informal helper expresses feelings of distress, anger, or depression"; and "Family or close friends report feeling overwhelmed by person's illness" —caregiver distress was defined. This definition has been used in previously published studies [23, 37, 38]. The selection of variables to test if they predict transfer of home care clients to a nursing home was based on previous literature and the researchers´ (IVK) clinical experience.

Statistical analysis

Descriptive statistics were used to summarize the characteristics of the sample at baseline, as well as the proportion of clients discharged from home care and the reasons for their discharge during the one-year study period.

To estimate changes in the physical and cognitive health of the clients, their care needs and the hours of home care they received over one year, mean and standard deviations were calculated for each variable at three time points (wave 1 at baseline, wave 2 after 6 months and wave 3 after 12 months) during the study period. These were gauged separately for each country and then compared with repeated ANOVA.

Home care clients were divided into two groups: 1) those still receiving home care after the one-year research period, and 2) those who had moved to a nursing home during the same period. Comparisons between these two groups were conducted using baseline data (wave 1), while information about nursing home admission was obtained from waves 2 and 3. Differences between groups were assessed based on various client conditions and characteristics. A chi-square test was applied to assess differences between groups at a significance level of $p<0.05$, and t-tests were conducted to examine whether continuous variables, such as age, scores on certain scales, and hours of formal care, influenced the likelihood of moving to a nursing home, maintaining the same significance threshold.

To identify variables for inclusion in a multiple logistic regression model, univariable logistic regression analyses were performed, separately for each country and all of them together, with the outcome being "still receiving home care" versus "moved to a nursing home. " Variables that achieved a significance level of $p < 0.05$ in either individual countries or across all four countries were evaluated and considered for inclusion (Appendix 1). Subsequently, backward selection was applied to refine the multiple logistic regression model which was created for all countries together. The variables that remained statistically significant after backward selection included, age, caregiver distress, whether the client or caregiver believed the client would be better off living elsewhere, a high score on the ADLH scale, the hours of formal care the client received, and whether the client believed their physical function could improve. These variables, along with gender, were included as independent variables in the multiple logistic regression model, with the dependent variable being the transition to a nursing home (i.e., moving vs. still receiving home care).

The software packages R for Windows 4.3.1 and RStudio 2023.23.1. were used to conduct these analyses.

Results

Participant characteristics

The characteristics of the home care clients who participated in the study are presented in Table 1. The overall mean age was 83.3 years, with the highest mean age in Germany (84.2 years), followed by Iceland (83.7 years). The majority of participants were female (69%). Only 27%, had partners, with the lowest percentage in Finland (16%), and the highest in Belgium, at 35%. Across the participating countries, 16% of clients did not have an informal caregiver, with significant variation between the countries. Caregiver distress among informal caregivers was highest in Iceland (34%) and lowest in Finland (9%).

Belgium had the highest mean score on most of the scales such as ADLH 3.2, DRS 1.8, and MAPLe 3.5, which may indicate that clients had worse health and a greater decline in abilities on average than the clients in the other participating countries. Iceland had the lowest mean score on the functional (ADLH 0.6), cognitive (CPS 1.1) and Maple scales (3.0). Bladder incontinence was relatively common across all countries, affecting nearly 80% of home care clients in Belgium, 51% in Germany, 43% in Iceland, and 40% in Finland.

In this study, the average number of hours of formal care per week was highest in Belgium (8.6 hours), and lowest in Iceland (3.6 hours). Only 10% of caregivers in Belgium believed that home care clients could improve their physical function compared to 49% in Finland.

Table 1 Baseline characteristics of the home care clients

	Overall	**Belgium**	**Finland**	**Germany**	**Iceland**	**P**
	N = 1.894	N = 525	N = 456	N = 493	N = 420	
Age, mean (SD)	83.3 (7.1)	82.4 (6.7)	82.9 (7.0)	84.2 (7.6)	83.7 (7.0)	<0.001
Female, n (%)	1.308 (69%)	352 (67%)	313 (69%)	351 (71%)	292 (70%)	0.600
Married, n (%)	503 (27%)	179 (35%)	71 (16%)	124 (25%)	129 (31%)	<0.001
Caregiver lives with the client						<0.001
No	984 (54%)	179 (40%)	331 (73%)	200 (41%)	274 (65%)	
Yes	544 (30%)	263 (60%)	46 (10%)	92 (19%)	143 (34%)	
No informal caregiver	283 (16%)	0 (0%)	79 (17%)	201 (41%)	3 (0.7%)	
Client would be better off elsewhere	199 (11%)	36 (7%)	30 (7%)	52 (11%)	81 (19%)	<0.001
Caregiver distress	351 (22%)	134 (28%)	35 (9%)	40 (14%)	142 (34%)	<0.001
ADLH score mean (SD)	1.7 (1.7)	3.2 (1.2)	0.8 (1.3)	2.2 (1.7)	0.6 (1.1)	<0.001
CPS score, mean (SD)	1.4 (1.5)	1.3 (1.6)	1.3 (1.2)	1.6 (1.7)	1.1 (1.2)	<0.001
CHESS score, mean (SD)	0.9 (1.0)	1.1 (1.0)	0.7 (0.9)	0.6 (0.9)	1.2 (1.0)	<0.001
DRS score, mean (SD)	1.4 (2.3)	1.8 (2.5)	0.9 (1.9)	1.6 (2.6)	1.2 (1.8)	<0.001
MAPLE score, mean (SD)	3.3 (1.2)	3.5 (0.8)	3.3 (1.3)	3.4 (1.2)	3.0 (1.3)	<0.001
Hours of formal care, mean (SD)	6.4 (6.5)	8.6 (7.7)	5.1 (5.2)	7.6 (6.7)	3.6 (3.8)	<0.001
Bladder incontinence, n (%)	1.025 (54%)	412 (80%)	181 (40%)	250 (51%)	182 (43%)	<0.001
CG[1] believes client can improve physical function	482 (26%)	52 (10%)	225 (49%)	74 (15%)	131 (31%)	<0.001
Client believes he/she can improve physical function	741 (39%)	64 (12%)	385 (84%)	122 (25%)	170 (40%)	<0.001

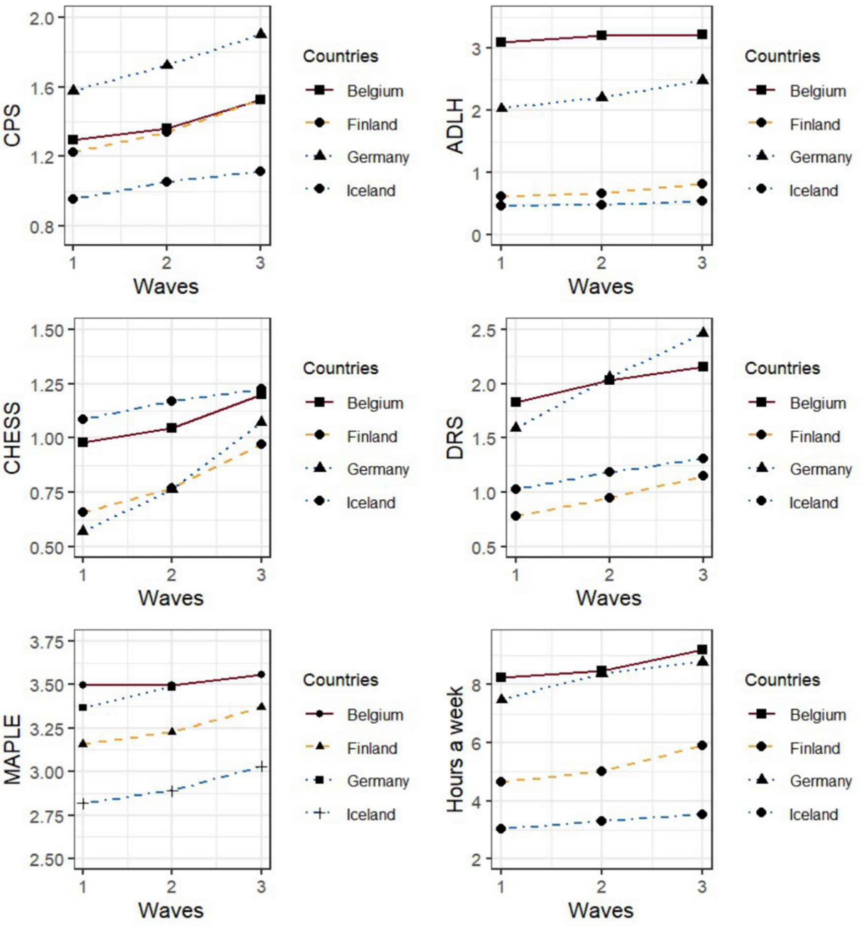
1) CaregiverADLH = Activities of Daily Living Hierarchy Scale; CPS = Cognitive Performance Scale; CHESS = Changes in Health, End-Stage Disease and Signs and Symptoms Scale; DRS = Depression Rating Scale; MAPLe = Method for Assigning Priority Levels Scale; Hours of formal care in average, the last seven days before the evaluation

One-way analysis of means (not assuming equal variances);

t-test were conducted for continuous variables: age, ADLH, CPS, CHESS, DRS, MAPLe and hours of formal care Pearson's Chi-squared test was used for cross-tabs analyses

Changes in health and abilities over one year

Among those home care clients who continued to live at home at the end of the one-year research period, a general decline in health and overall ability was observed, as shown in Figure 2. There are significant differences



Repeated ANOVA

	CPS	ADLH	CHESS	DRS	MAPLe	Hours a week
Countries	<0.001	0.000	<0.001	<0.001	<0.001	<0.001
Waves	<0.001	<0.001	<0.001	<0.001	0.002	0.001
Interaction of countries and waves	0.775	0.061	0.011	0.125	0.605	0.685

CPS = Cognitive Performance Scale; ADLH = Activities of Daily Living Hierarchy Scale; CHESS = Changes in Health, End-Stage Disease and Signs and Sympoms Scale; DRS = Depression Rating Scale; MAPLe = Method for Assigning Priority Levels Scale; Hours a week = Hours of formal care in average, the last seven days before the evaluation

Figure 2 Changes in health, overall ability, and formal care of home care clients continuing to receive home care service: a one-year follow-up.

Comparison between countries and waves ((1, baseline; 2, at 6 months, 3, at 12months) across countries for all scales (CPS, ADLH, CHESS, DRS, MAPLe) and for formal care, with *p*-values of <0.001 or 0.000 for each scale. Significant differences were observed across waves for all scales and formal care, with *p*-values <0.05. The interaction between countries and waves was statistically significant for CHESS (p = 0.011) but not for the other variables.

Average scores on the cognitive (CPS), depressive (DRS), and CHESS scales increased, with the smallest change noted on the physical function scale (ADLH). Additionally, the average number of formal care hours increased across all countries, with the most significant rise observed in Finland, from 4.9 to 6.0 hours per week.

Clients discharged from Home Care

Home care clients were discharged for a variety of reasons. Some of the participants had been receiving support due to temporary conditions, while others had regained their independence and no longer required home care. Others were discharged to receive care in other parts of the healthcare system, such as health centers. Some of the home care clients (12%) moved to nursing homes despite receiving formal assistance, while others died (10%). During the research year, 30% of participants were discharged from home care. The highest rate was in Iceland, where nearly 35% of home care clients were discharged; in Belgium, it was 33% and in Germany 27%. The lowest rate was in Finland at 26%. As shown in Figure 2, the highest rate of home care clients moving to a nursing home was in Iceland (18%), followed by Finland (13%), Belgium (12%), and Germany (7%). In Germany, the highest percentage of participants (14%) died during the research period, followed by 11% in Belgium, 10% in Iceland, and 2% in Finland.

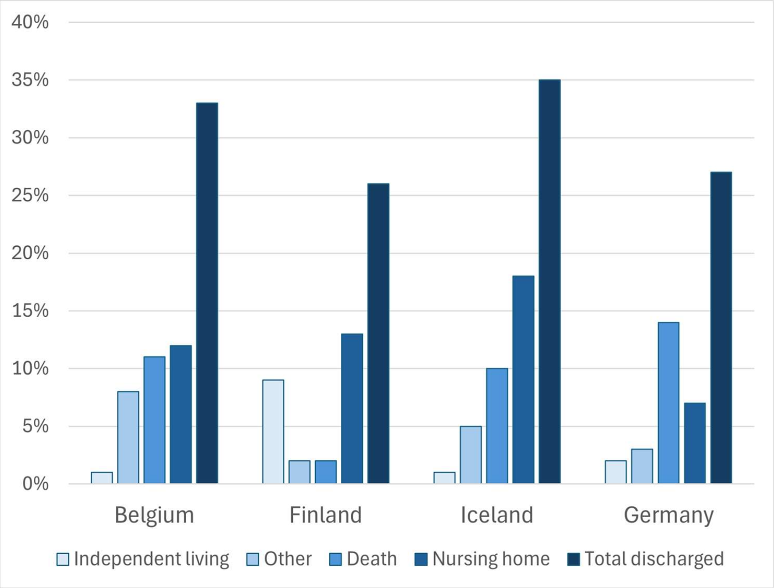


Figure 3 Proportion of home care clients discharged from home care for various reasons during one-year follow-up

Factors associated with individuals moving to a nursing home

The sociodemographic and health characteristics of home care clients, stratified by those still receiving home care versus those who transitioned to a nursing home, are presented in Table 2. Predictive factors for nursing home admission varied considerably across the four countries. In Belgium, clients who moved to nursing homes were significantly older than those still living at home (mean age: 84.4 years [5.5] vs 81.9 years [6.8], p<0.05). Similarly, in Finland the transitioning group was older (mean age: 84.8 years [5.6] vs 82.5 years [7.2], p<0.05). However, this age difference was not observed in Germany and Iceland. Among those who moved to a nursing home, a higher proportion did not live with a caregiver, except in Iceland (refer to Table 2 for details).

Caregiver distress was significantly higher among people caring for clients who transitioned to a nursing home in Iceland (58% vs. 25%, $p < 0.001$), while this difference was less pronounced in other countries. A higher proportion of home care clients moved to nursing homes when either the client or their caregiver responded affirmatively that they believed the client would be better off living elsewhere. This difference was statistically significant in Belgium (20% vs. 5%, *p* < 0.001), Germany (27% vs. 7%, *p* < 0.001), and Iceland (35% vs. 15%, *p* < 0.001); however, in Finland, the difference was not statistically significant (7% vs. 5%, *p* = 0.8).

Table 2 Characteristics and health and functional abilities of those who moved to a nursing home and those who continued to receive home care in the four countries during 12-month follow-up

	Overall			Belgium			Finland			Germany			Iceland		
	Home care	**Nursing home**		**Home care**	**Nursing home**		**Home care**	**Nursing home**		**Home care**	**Nursing home**		**Home care**	**Nursing home**	
	N = 1262	**N = 231**	**P**	**N = 355**	**N = 63**	**P**	**N = 324**	**N = 58**	**P**	**N = 310**	**N = 33**	**P**	**N = 273**	**N = 77**	**P**
Age, mean (SD)	82.8 (7.2)	84.1 (6.4)	0.009	81.9 (6.8)	84.4 (5.5)	0.002	82.5 (7.2)	84.8 (5.6)	0.008	83.7 (7.8)	83.4 (6.1)	0.800	83.5 (6.9)	83.5 (7.7)	>0.900
Female, n (%)	886 (70%)	156 (68%)	0.500	243 (68%)	40 (63%)	0.500	224 (69%)	39 (67%)	0.900	220 (71%)	23 (70%)	>0.900	199 (73%)	54 (70%)	0.700
Married	318 (25%)	60 (26%)	0.800	119 (34%)	20 (34%)	>0.900	55 (17%)	7 (12%)	0.500	71 (23%)	7 (21%)	>0.900	73 (27%)	26 (34%)	0.300
Caregiver lives with the client			0.002			0.045			0.800			0.071			0.600
No	661 (55%)	143 (64%)		115 (40%)	30 (56%)		237 (73%)	44 (76%)		123 (40%)	19 (58%)		186 (68%)	50 (65%)	
Yes	340 (28%)	62 (28%)		174 (60%)	24 (44%)		31 (9.6%)	6 (10%)		49 (16%)	6 (18%)		86 (32%)	26 (34%)	
No helper	195 (16%)	17 (7.7%)		0 (0%)	0 (0%)		56 (17%)	8 (14%)		138 (45%)	8 (24%)		1 (0.4%)	1 (1.3%)	
Client would be better off elsewhere	98 (7.8%)	52 (23%)	<0.001	17 (4.9%)	12 (20%)	<0.001	17 (5.2%)	4 (6.9%)	0.800	23 (7.4%)	9 (27%)	<0.001	41 (15%)	27 (35%)	<0.001
Caregiver distress	189 (18%)	69 (33%)	<0.001	81 (25%)	18 (31%)	0.500	19 (7.1%)	4 (8.0%)	>0.900	19 (11%)	3 (12%)	>0.9	70 (26%)	44 (58%)	<0.001
ADLH score	1.6 (1.7)	1.8 (1.6)	0.200	3.1 (1.2)	3.0 (1.1)	0.500	0.6 (1.2)	1.4 (1.7)	0.003	2.0 (1.7)	2.1 (1.6)	0.900	0.5 (1.0)	0.9 (1.2)	0.001
CPS score	1.3 (1.4)	1.6 (1.5)	0.002	1.3 (1.6)	1.6 (1.7)	0.200	1.2 (1.1)	1.5 (1.4)	0.200	1.6 (1.7)	1.7 (1.4)	0.700	1.0 (1.1)	1.6 (1.4)	<0.001
CHESS score	0.8 (0.9)	1.1 (1.1)	<0.001	1.0 (0.9)	1.3 (1.1)	0.023	0.7 (0.9)	0.8 (0.9)	0.400	0.6 (0.8)	0.9 (1.2)	0.120	1.1 (0.9)	1.3 (1.1)	0.063
DRS score	1.3 (2.3)	1.4 (2.1)	0.700	1.8 (2.7)	1.6 (1.9)	0.300	0.8 (1.6)	1.1 (1.5)	0.200	1.6 (2.6)	1.7 (3.3)	0.900	1.0 (1.8)	1.4 (2.1)	0.200
MAPLE score	3.2 (1.2)	3.6 (1.1)	<0.001	3.5 (0.8)	3.6 (0.8)	0.500	3.2 (1.4)	3.5 (1.1)	0.021	3.4 (1.2)	3.4 (1.3)	>0.900	2.8 (1.4)	3.6 (1.1)	<0.001
Hours of formal care1)	6.1 (6.0)	6.7 (6.0)	0.200	8.3 (6.7)	9.1 (7.2)	0.400	4.6 (4.4)	6.6 (5.4)	0.013	7.8 (6.8)	4.7 (5.3)	0.004	3.0 (3.3)	5.7 (5.0)	<0.001
Bladder incontinence	653 (52%)	143 (62%)	0.004	274 (78%)	51 (84%)	0.400	113 (35%)	29 (50%)	0.041	153 (49%)	18 (55%)	0.700	113 (41%)	45 (58%)	0.012
CG2) **believes client can improve physical function**	348 (28%)	40 (18%)	0.002	37 (11%)	4 (6.8%)	0.500	172 (53%)	18 (31%)	0.003	54 (17%)	3 (9.1%)	0.300	85 (31%)	15 (19%)	0.063
Client believes he/she can improve physical function	515 (41%)	89 (39%)	0.600	47 (13%)	8 (13%)	>0.900	276 (85%)	48 (83%)	0.800	80 (26%)	11 (33%)	0.500	112 (41%)	22 (29%)	0.064

In both Finland (1.4 [1.7] vs. 0.6 [1.2], *p* < 0.05) and Iceland (0.9 [1.2] vs. 0.5 [1.0], *p* < 0.001), physical function, as measured by the ADLH scale, was significantly worse among those who moved to nursing homes. Also, in Finland (3.5 [1.1]vs. 3.2 [1.4]), *p* < 0.05) and Iceland (3.6 [1.1] vs. 2.8 [1.4], *p* < 0.001), clients who transitioned to nursing homes had significantly higher MAPLe scores compared to those who continued living at home. Additionally, these clients received more hours of formal care on average, with Finland showing a significant increase in care hours (6.6 [5.4] vs. 4.6 [4.4], *p* < 0.05) and as well as Iceland (5.7 [5.0] vs. 3.0 [3.3], *p* < 0.001) (Table 2).

Factors predicting transition from home care to nursing home

Table 3 presents the multiple logistic regression model predicting home care clients moving to a nursing home. The odds of moving to a nursing home were higher in Belgium (OR = 6.6, 95% CI = 2.6 to 16.4) and Germany (OR = 3.8, 95% CI = 1.2 to 11.4) if the older person or their caregiver believed the individual would be better off living elsewhere, and the result were statistically significant in both cases. In Iceland, caregiver distress was the strongest significant predictor of a home care client moving to a nursing home (OR = 3,2, 95% CI = 1.7 to 6.0), while scoring ≥3 on the ADLH scale increased the likelihood in Finland (OR = 2.9, 95% CI = 1.3 to 6.5). Additionally, if the home care client believed they could improve their physical function, the odds of transfer to a nursing home were reduced by 53% in Belgium, 57% in Finland, 52% in Germany, and 35% in Iceland.

Table 3 Multiple logistic regression analysis of risk factors for moving to a nursing home within 12 months

	Overall			**Belgium**			**Finland**			**Germany**			**Iceland**		
	(n=1227)			(n=364)			(n=318)			(n=197)			(n=348)		
Moved to a nursing home	231 (12%)			63 (12%)			58 (13%)			33 (7%)			77 (18%)		
	OR	**95% CI**	**P**	**OR**	**95% CI**	**P**	**OR**	**95% CI**	**P**	**OR**	**95% CI**	**P**	**OR**	**95% CI**	**P**
Age of the client	1.03	(1.01, 1.05)	0.01	1.07	(1.02, 1.13)	0.01	1.05	(1.00, 1.11)	0.06	0.99	(0.93, 1.05)	0.69	1.01	(0.98, 1.06)	0.48
Client is female	0.87	(0.62, 1.23)	0.42	0.79	(0.42, 1.51)	0.46	0.78	(0.38, 1.63)	0.49	1.06	(0.42, 2.92)	0.90	1.03	(0.56, 1.97)	0.92
Caregiver distress	1.63	(1.13, 2.33)	0.01	1.12	(0.53, 2.23)	0.76	0.67	(0.17, 2.08)	0.52	0.72	(0.14, 2.66)	0.65	3.24	(1.76, 6.00)	0.00
Client would be better off elsewhere	2.88	(1.89, 4.36)	0.00	6.61	(2.66, 16.39)	0.00	0.93	(0.22, 3.04)	0.90	3.79	(1.21, 11.43)	0.02	1.27	(0.62, 2.55)	0.50
Client ADLH score ≥3	0.89	(0.63, 1.26)	0.51	0.6	(0.28, 1.35)	0.20	2.87	(1.25, 6.45)	0.01	1.67	(0.67, 4.22)	0.27	0.83	(0.31, 2.07)	0.69
Hours of formal care[1]	1.03	(1.00, 1.06)	0.04	1.00	(0.96, 1.05)	0.89	1.06	(0.99, 1.13)	0.07	0.95	(0.85, 1.04)	0.35	1.15	(1.06, 1.26)	0.00
Client belives he/she can improve physical function	0.57	(0.37, 0.84)	0.01	0.47	(0.11, 1.45)	0.24	0.43	(0.21, 0.84)	0.01	0.49	(0.07, 1.90)	0.36	0.65	(0.33, 1.24)	0.21

ADLH = Activities of Daily Living Hierarchy Scale

[1] Hours of formal care, in average, the last seven days before the evaluation

Discussion

In this study the physical and mental health of the home care clients who remained at home by the end of the one-year study period had generally worsened. The data indicate that formal assistance increased across all countries, suggesting that the rise in care needs was met by an increase in the number of hours provided by formal services. This suggests that older people with significant care needs can remain at home longer if they receive greater assistance.

These findings indicate an opportunity for action by increasing public support particularly in Iceland and Finland, where service hours are noticeably lower than elsewhere, so that older people with comparable impairments and care needs to those in other countries can continue to live at home.

This study identified several key factors that show difference between those who stay at home or move to a nursing home and others that predict the transition from home care to nursing homes among older people across four European communities. The results show that higher levels of physical dependency (high ADLH scores, bladder incontinence), cognitive impairment, caregiver distress, and a perception by either the caregiver or client that the client would be better off living elsewhere are important predictors of nursing home admission across countries. Additionally, the belief that home care clients can improve their physical function is associated with a reduced likelihood of them moving to a nursing home, although this was only statistically significant in Finland. In addition to these findings, which were consistent for all the participating countries, considerable variations were observed that will be discussed below.

In this study, 12% of home care clients across the four countries moved to a nursing home during the one-year research period, with the highest proportion in Iceland (18%), followed by 13% in Finland, 12% in Belgium, and 7% in Germany. Other Finnish studies have reported both a higher percentage than this study, 17.6% [39], and a lower one: 9.2% [21]. When focusing solely on the Nordic countries, in the AdHOC study [40] the rate was 10% [20] and in a study in Canada, 8.7% [16].

Consistent with published studies [10, 21, 39], those clients who moved to nursing homes in Finland and Iceland in this study had significantly worse physical functioning compared with those who remained at home. No significant difference was observed in Belgium and Germany. Home care clients with greater need for service, as indicated by higher average scores on the MAPLe scale, were more likely to move to a nursing home. This was true for all the participating countries except Germany, where the average MAPLe score was the same regardless of whether the client remained at home or had moved to a nursing home during the study period. The difference was statistically significant in Finland and Iceland. These findings are consistent with results from other studies [20-22, 39].

The findings of this study suggest that formal services do respond to increasing care needs, as evidenced by the fact that in Belgium, and significantly in Finland, and Iceland, those who moved to a nursing home had received more hours in assistance before the transfer than those who remained at home. By contrast, the opposite trend was observed in Germany, where individuals still living at home received significantly more hours of assistance on average (7.8 hours) compared with those who moved to a nursing home (4.7 hours). This indicates that the formal care system in Germany may be able to provide more substantial support at home compared with the other participating countries.

The variable that proved to be the strongest predictor of nursing home transferal, overall, was when the client and/or caregiver believed that the client would be better off living elsewhere. “Elsewhere” might imply that the individual would be less isolated, have their needs better met, or experience greater safety in a nursing home or other supportive housing. This variable was statistically significant in both Belgium and Germany. It was also a significant predictor for moving to a nursing home in four Nordic capitals more than decade ago [20].

Research findings are inconsistent regarding the effect of depression and moving to a nursing home. In the present study, no significant difference was found between those who remained at home and those who moved to a nursing home, which is in line with the findings of Björkstedt [21]. However, other studies have demonstrated the predictive value of depression for nursing home admission [15, 16, 19]. In the present study, a higher proportion of home care clients transitioned to a nursing home when their caregiver experienced caregiver distress, compared to those whose caregivers were not distressed. This was observed despite findings indicating that home care clients in Iceland generally have better health and functional abilities, resulting in lower care needs compared to those in other European countries [4, 24]. The largest difference in nursing home admission rates associated with caregiver distress was observed in Iceland, where this association was statistically significant, which is consistent with previous findings [22, 23].

It is important for home care nurses to understand which factors predict nursing home admission so they can intervene where possible. They also need to be aware of factors that may offer protection against moving to a nursing home. This study reveals that when clients believe they can improve their physical function, the likelihood of moving to nursing homes decreases across all countries but only to a significant degree in Finland. Confidence in one's ability to improve physical function acts as a protective factor, as individuals with greater self-efficacy are more likely to maintain independence [41]. These findings are consistent with previous research, which demonstrates that a higher proportion of older people who perceive their health as good or very good remain at home, while those who perceive their health as poor or very poor are more likely to move to a nursing home [15, 21].

Older people have expressed prerequisites to being able to continue living at home, for example a certain degree of reciprocal support, available services, and having someone to turn to for help when needed [42]. This study suggests that in Belgium and Germany, where more extensive home care services are provided, clients with poorer physical and cognitive abilities remain at home longer compared to clients in Finland and Iceland, who have better abilities. In contrast, Iceland has the highest proportion of clients moving to nursing homes, which may be linked to the limited formal care hours available. It has been shown that support provided by an interdisciplinary team led to reduced admissions to nursing homes and hospitals, fewer falls, and improvements in physical function [43]. When older people with mild to moderate or severe impairments received either single- or multicomponent interventions, it reduced or delayed admissions to nursing homes [44]. In previously published studies, actions found to reduce the risk of nursing home admission included receiving higher-quality primary care, co-resident caregiving, integrated medical and long-term care services, intensive formal home support, and the use of short-stay services [9].

Reducing the risk of residential aged care admission requires complex, multifactorial interventions. By comparison, single-focus approaches have shown limited effectiveness. A meta-analysis demonstrates that such nuanced interventions can lower the risk of nursing home admission, particularly for individuals with dementia [45]. Given the complexity of aging and chronic health conditions, it is clear that multifaceted interventions are crucial. As the population continues to age, understanding which elements of interventions contribute to their success becomes increasingly important.

A standardized assessment tool, such as the interRAI-HC, can aid nurses in identifying risk factors related to clients' health and functional abilities, as demonstrated in this study. Assessing each client individually is crucial, as risk factors and the overall ability to remain at home vary significantly between individuals, highlighting the value of such tools in helping healthcare professionals develop more effective care plans to support older people in staying at home longer.

Overall, the findings highlight the need for targeted interventions that address both the physical and emotional needs of home care clients and their caregivers to support aging in place with the goal of delaying transitions to institutional care. Government policy and the preference of older people is to remain living in their own homes for as long as possible. Variability in predictors across the participating countries emphasizes the importance of tailoring care interventions to local contexts. The goal of public services is to provide support to disabled home care clients, enabling them to live at home for as long as possible, thereby delaying or preventing the need for moving to a nursing home.

Strength and limitations

The strength of this study is the use of the internationally validated and reliable interRAI-HC assessment, which enables meaningful comparisons across countries and timeframes. This tool is client-centered and based on standardized evaluation by trained assessors. This ensures accuracy and consistency of the data. In addition, the study benefits from a one-year follow-up period, allowing us to track the clients' outcomes over time — noting whether they are still receiving home care, have moved to a nursing home, or have experienced other significant changes in their care. The study was conducted simultaneously in six European countries which gives an opportunity for comparison. The study gives an opportunity to understand the relationship between overall ability and nursing home admission.

A limitation of the study is that the participating home care organizations were selected based on diverse care practices, including differences in location, size, management, and form of payment, rather than being representative of the entire country. Consequently, the applicability of these findings is limited, and should be interpreted accordingly. However, the sample in Iceland is representative of home care clients in the capital area, where over 60% of the country´s population resides. Cross-country comparisons are challenging, like in this study were cultural and organizational variables were not available for inclusion.

Conclusion

By identifying the factors that predict the likelihood of a transition from home care to a nursing home, nurses, other healthcare professionals, caregivers, and policymakers can make better-informed decisions and service plans. A comprehensive approach is vital for supporting older people to live at home, while ensuring a smooth transition when needed. Understanding these predictors enables the development of targeted interventions, allowing older people to maintain their independence for as long as possible by ensuring appropriate care when necessary.

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Appendix 1

N=1493		**All 4 countries**			**Belgium**			**Finland**			**Iceland**			**Germany**		
Variables names in interRAI	**Variables explanation**	**Beta**	**OR**	**p**	**Beta**	**OR**	**p**	**Beta**	**OR**	**p**	**Beta**	**OR**	**p**	**Beta**	**OR**	**p**
iA3	Age	0,025	1,025	0,016	0,061	1,062	0,006	0,049	1,051	0,0246	0	1	0,9997	-0,004	0,996	0,861
iA2	Gender (recode 1=Male, 0=Female)	0,125	1,133	0,416	0,221	1,248	0,439	0,087	1,091	0,7742	0,136	1,145	0,6324	0,061	1,063	0,879
	Caregiver distress (iP2a, iP2b, iF7d combined)	0,811	2,250	< 0.001	0,408	1,504	0,203	0,151	1,163	0,7953	1,390	4,015	< 0.001	0,044	1,045	0,948
iA12c	Better off living elsewhere (no vs other community residence	1,286	3,617	< 0.001	1,758	5,800	< 0.001	0,250	1,284	0,6683	1,135	3,112	< 0.001	1,552	4,722	0,001
sCPS	CPS scale (recode <3 vs ≥3)	0,453	1,572	0,012	0,593	1,809	0,082	0,402	1,495	0,3757	1,233	3,433	< 0.001	0,213	1,237	0,598
sDRS	DRS scale (recode <3 vs ≥3)	0,113	1,119	0,532	-0,063	0,939	0,848	0,844	2,325	0,0311	0,161	1,174	0,6374	-0,156	0,855	0,728
sMAPLE	MAPLE scale (recode <4 vs ≥4)	0,404	1,498	0,007	0,176	1,193	0,575	0,299	1,349	0,3047	0,929	2,532	< 0.001	0,063	1,065	0,866
sCHESS	CHESS scale (recode <3 vs ≥3)	0,897	2,451	0,000	1,144	3,139	0,014	0,085	1,088	0,8963	0,924	2,519	0,0261	1,232	3,428	0,079
sADLH	ADLH scale (recode <3 vs ≥3)	0,078	1,081	0,600	-0,359	0,698	0,280	1,452	4,271	< 0.001	0,805	2,236	0,0463	0,130	1,139	0,724
iH1	Bladder incontinence	0,427	1,532	0,004	0,284	1,328	0,449	0,632	1,881	0,0294	0,720	2,055	0,0067	0,218	1,243	0,555
	Formal care-hours (iN3ab, iN3bbR, iN3cb combined)	0,017	1,018	0,125	0,016	1,016	0,424	0,075	1,078	0,0055	0,174	1,191	< 0.001	-0,097	0,907	0,015
iG7a	Client believes he/she can improve physical function	-0,572	0,564	0,002	-0,421	0,657	0,444	-0,903	0,405	0,0033	-0,637	0,529	0,0445	-0,757	0,469	0,225
iA4	Marital status (recode with partner vs no partner)	0,068	1,071	0,691	0,048	1,050	0,883	-0,384	0,681	0,3833	0,330	1,390	0,2572	-0,133	0,876	0,773
iJ2a	Difficult or unable to stand up	0,442	1,556	0,002	0,236	1,266	0,409	0,582	1,789	0,0524	0,666	1,946	0,0114	0,166	1,181	0,666
iJ1	Falls (recode no fall last 90 days vs one or more falls)	0,373	1,452	0,028	-0,106	0,899	0,744	0,792	2,207	0,0133	0,629	1,875	0,0417	-0,362	0,697	0,566
iJ2d	Unsteady gait	0,485	1,625	0,003	-0,148	0,862	0,627	0,558	1,747	0,0785	0,855	2,351	0,0254	0,331	1,392	0,377
iJ2c	Dizziness	0,076	1,079	0,612	-0,284	0,752	0,360	0,096	1,100	0,7452	-0,290	0,748	0,2733	0,820	2,27	0,030
iK3	Normal nutritional intake vs problems with nutritional intake	0,349	1,418	0,121	0,405	1,499	0,195	-0,309	0,734	0,7765	1,184	3,266	0,0399	0,261	1,298	0,687
iI1h	Parkonsons disease	0,544	1,723	0,047	1,083	2,953	0,019	0,448	1,564	0,5055	0,943	2,566	0,0512	-15,41	2E-07	0,986
iG6b	Didn´t go out in the last 3 days vs usually goes out	-0,361	0,697	0,018	-0,684	0,505	0,024	-0,292	0,747	0,330	-0,553	0,575	0,0494	-0,041	0,959	0,914
iF1d	Loneliness	0,254	1,289	0,110	-0,055	0,946	0,862	0,757	2,132	0,0123	0,202	1,224	0,5139	0,350	1,419	0,362
iL1	Pressure ulcer (0=no, 1=skin redness, 2=pressure ulcer)	0,454	1,575	0,094	0,443	1,557	0,330	1,650	5,206	0,0026	0,356	1,428	0,5575	-1,015	0,362	0,330
iG7b	Caregiver believes he/she can improve physical function	-0,062	0,940	0,675	0,083	1,087	0,841	-0,101	0,904	0,793	-0,570	0,566	0,0438	0,357	1,429	0,369
iP1b1	Living with informal helper (1=Yes)	0,890	2,435	< 0.001				0,120	1,128	0,7777	-1,298	0,273	0,3644	0,997	2,711	0,024
iP1b1	Living with informal helper (8=no informal helper)	0,729	2,073	0,012	-0,557	0,573	0,072	0,248	1,282	0,6739	-1,199	0,301	0,4036	0,728	2,071	0,202
iJ7	Self-reported health (1=good or excellent)	-0,374	0,688	0,070	0,138	1,148	0,674	-0,372	0,689	0,392	-0,897	0,408	0,0148	-1,034	0,356	0,434
iJ7	Self-reported health (8=could or would not respond)	-0,550	0,577	0,003	0,718	2,050	0,235	-0,056	0,945	0,9213	1,817	6,155	0,0393	-1,044	0,352	0,210

Appendix A

Univariable logistic regression analysis for the outcome "still receiving home care" versus "moved to a nursing home," conducted separately for each country and for all four countries together

N=1493		All 4 countries			Belgium			Finland			Iceland			Germany		
Variables names in interRAI	Variables explanation	Beta	OR	p	Beta	OR	p	Beta	OR	p	Beta	OR	p	Beta	OR	p
iA3	Age	0,025	1,025	0,016	0,061	1,062	0,006	0,049	1,051	0,0246	0	1	0,9997	-0,004	0,996	0,861
iA2	Gender (recode 1=Male, 0=Female)	0,125	1,133	0,416	0,221	1,248	0,439	0,087	1,091	0,7742	0,136	1,145	0,6324	0,061	1,063	0,879
	Caregiver distress (iP2a, iP2b, iF7d combined)	0,811	2,250	< 0.001	0,408	1,504	0,203	0,151	1,163	0,7953	1,390	4,015	< 0.001	0,044	1,045	0,948
iA12c	Better off living elsewhere (no vs other community residence	1,286	3,617	< 0.001	1,758	5,800	< 0.001	0,250	1,284	0,6683	1,135	3,112	< 0.001	1,552	4,722	0,001
sCPS	CPS scale (recode <3 vs ≥3)	0,453	1,572	0,012	0,593	1,809	0,082	0,402	1,495	0,3757	1,233	3,433	< 0.001	0,213	1,237	0,598
sDRS	DRS scale (recode <3 vs ≥3)	0,113	1,119	0,532	-0,063	0,939	0,848	0,844	2,325	0,0311	0,161	1,174	0,6374	-0,156	0,855	0,728
sMAPLE	MAPLE scale (recode <4 vs ≥4)	0,404	1,498	0,007	0,176	1,193	0,575	0,299	1,349	0,3047	0,929	2,532	< 0.001	0,063	1,065	0,866
sCHESS	CHESS scale (recode <3 vs ≥3)	0,897	2,451	0,000	1,144	3,139	0,014	0,085	1,088	0,8963	0,924	2,519	0,0261	1,232	3,428	0,079
sADLH	ADLH scale (recode <3 vs ≥3)	0,078	1,081	0,600	-0,359	0,698	0,280	1,452	4,271	< 0.001	0,805	2,236	0,0463	0,130	1,139	0,724
iH1	Bladder incontinence	0,427	1,532	0,004	0,284	1,328	0,449	0,632	1,881	0,0294	0,720	2,055	0,0067	0,218	1,243	0,555
	Formal care-hours (iN3ab, iN3bbR, iN3cb combined)	0,017	1,018	0,125	0,016	1,016	0,424	0,075	1,078	0,0055	0,174	1,191	< 0.001	-0,097	0,907	0,015
iG7a	Client believes he/she can improve physical function	-0,572	0,564	0,002	-0,421	0,657	0,444	-0,903	0,405	0,0033	-0,637	0,529	0,0445	-0,757	0,469	0,225
iA4	Marital status (recode with partner vs no partner)	0,068	1,071	0,691	0,048	1,050	0,883	-0,384	0,681	0,3833	0,330	1,390	0,2572	-0,133	0,876	0,773
iJ2a	Difficult or unable to stand up	0,442	1,556	0,002	0,236	1,266	0,409	0,582	1,789	0,0524	0,666	1,946	0,0114	0,166	1,181	0,666
iJ1	Falls (recode no fall last 90 days vs one or more falls)	0,373	1,452	0,028	-0,106	0,899	0,744	0,792	2,207	0,0133	0,629	1,875	0,0417	-0,362	0,697	0,566
iJ2d	Unsteady gait	0,485	1,625	0,003	-0,148	0,862	0,627	0,558	1,747	0,0785	0,855	2,351	0,0254	0,331	1,392	0,377
iJ2c	Dizziness	0,076	1,079	0,612	-0,284	0,752	0,360	0,096	1,100	0,7452	-0,290	0,748	0,2733	0,820	2,27	0,030
iK3	Normal nutritional intake vs problems with nutritional intake	0,349	1,418	0,121	0,405	1,499	0,195	-0,309	0,734	0,7765	1,184	3,266	0,0399	0,261	1,298	0,687
iI1h	Parkonsons disease	0,544	1,723	0,047	1,083	2,953	0,019	0,448	1,564	0,5055	0,943	2,566	0,0512	-15,41	2E-07	0,986
iG6b	Didn´t go out in the last 3 days vs usually goes out	-0,361	0,697	0,018	-0,684	0,505	0,024	-0,292	0,747	0,330	-0,553	0,575	0,0494	-0,041	0,959	0,914
iF1d	Loneliness	0,254	1,289	0,110	-0,055	0,946	0,862	0,757	2,132	0,0123	0,202	1,224	0,5139	0,350	1,419	0,362
iL1	Pressure ulcer (0=no, 1=skin redness, 2=pressure ulcer)	0,454	1,575	0,094	0,443	1,557	0,330	1,650	5,206	0,0026	0,356	1,428	0,5575	-1,015	0,362	0,330
iG7b	Caregiver believes he/she can improve physical function	-0,062	0,940	0,675	0,083	1,087	0,841	-0,101	0,904	0,793	-0,570	0,566	0,0438	0,357	1,429	0,369
iP1b1	Living with informal helper (1=Yes)	0,890	2,435	< 0.001				0,120	1,128	0,7777	-1,298	0,273	0,3644	0,997	2,711	0,024
iP1b1	Living with informal helper (8=no informal helper)	0,729	2,073	0,012	-0,557	0,573	0,072	0,248	1,282	0,6739	-1,199	0,301	0,4036	0,728	2,071	0,202
iJ7	Self-reported health (1=good or excellent)	-0,374	0,688	0,070	0,138	1,148	0,674	-0,372	0,689	0,392	-0,897	0,408	0,0148	-1,034	0,356	0,434
iJ7	Self-reported health (8=could or would not respond)	-0,550	0,577	0,003	0,718	2,050	0,235	-0,056	0,945	0,9213	1,817	6,155	0,0393	-1,044	0,352	0,210