Care and support in later life: A study on the dynamics of care networks of frail, community-dwelling older adults

Deborah Lambotte

Supervisors: Prof. Dr. Martinus J. M. Kardol
Prof. Dr. Liesbeth De Donder

A thesis submitted in fulfilment of the requirements for the degree of PhD in 'Pedagogische Wetenschappen, richting Agogische Wetenschappen', Faculty of Psychology and Educational Sciences, Department of Educational Sciences

Adult Educational Sciences

Vrije Universiteit Brussel

October 2018

This research was supported by a grant from the Flemish government agency for Innovation by Science and Technology [IWT-140027 SBO].

Dissertation committee

Supervisors

Prof. Dr. Martinus J. M. Kardol
Leerstoel Bevordering Active Ageing
Universiteit Brussel

Prof. Dr. Liesbeth De Donder
Faculty of Psychology and Educational Sciences
Department of Educational Sciences
Vrije Universiteit Brussel

Exam Committee

Prof. Dr. Free De Backer
Department of Educational Sciences
Faculty of Psychology and Educational Sciences
Vrije Universiteit Brussel

Prof. Dr. An Jacobs
Department of Communication Sciences
Faculty of Economic and Social Sciences and Solvay Business School
Vrije Universiteit Brussel

Prof. Dr. Céline J. Mahieu
School of Public Health
Université Libre de Bruxelles

Prof. Dr. Mirella Minkman
Innovation of organization and governance of integrated long term care (Vilans Chair)
TIAS School for Business and Society

Acknowledgments

"It's a dangerous business, Frodo, going out your door. You step onto the road, and if you don't keep your feet there's no knowing where you might be swept off to."
J.R.R. Tolkien

This dissertation made me undertake quite a journey these last four years. It all started with a conversation with Liesbeth, offering me the possibility to do a PhD. I still hear her say: "*Deborah, you must know that this research group is like a rowboat. Each of us is on this boat, each of us has various tasks and responsibilities but we all row together.*" Those words convinced me to start my PhD in January 2015. This PhD has been a great adventure and offered me many opportunities, enriching experiences and great memories. I also had the chance to meet wonderful people. This dissertation is not only the result of a lot of reading, data collection, analysing and writing, but also of great support and encouragements from people who were close to me. For that, a word of gratitude is in order.

Liesbeth, thank you for giving me this opportunity four years ago and for being my supervisor. I admire your competences and dedication to all of us. Thank you for all the opportunities you gave me, your advice, guidance and confidence. I learned a lot from you; how to handle research issues, doing statistics, making presentations, writing research articles, etc. It is incredible how just one phone call or e-mail from you in times of crisis would make everything alright again. You always had the right words and feedback. I am convinced that all of this has contributed not only to my research skills but also to my personal development.
Tinie, I am very grateful for having you as a supervisor as well. Thank you for your support, advice and for sharing your opinion. Our talks always motivated me. Also, thank you for giving me the opportunity to go to Vughterstede and let me interview some of the habitants. It was a very enriching experience.

A very special thank you goes to Dominique and Nico. As part of my guidance committee, I had the chance to receive valuable feedback and insights from both of you. Thank you for always sharing your points of view and expertise. Also, thank you for involving me in all kinds of projects. I learned a lot through my involvement in the development of the evaluation grid for informal caregivers and the co-create project. Dominique, thank you for teaching me how to network and how to translate our research work to practice. The way you look at research always inspired me. Also thank you for involving me in the course 'Agogische Perspectieven op Active Ageing'. I really enjoyed teaching by your side.

Besides great mentors, I was lucky to work with fantastic colleagues. I was very fortunate to spend my PhD time in office 3B241, with Minne, Tina, Bram and Daan. You are four wonderful colleagues. Thank you for your support, encouragements, for being so enthusiastic all the time and for allowing me to play my 'cheesy' music once in a while. Minne, a special thanks goes to you. Thank you for listening and for cheering me up in times of crisis, you were always there when I needed someone to lean on. A big thank you goes to all my other co-researchers of the 'staf' as well. An-Sofie, Sarah, Dorien, Sofie, Renfeng, Flore, Lise, Sylvia, Bram and Emily, thank you for helping and advising me when needed, for letting me participate in abstracts, articles, presentations and projects, for the great times at the office, at conferences and other places, etc. I believe we make a wonderful team. Furthermore, I would like to thank our Department of Educational Sciences. I had memorable moments with many of my EDWE colleagues, and they have in some way or another contributed to where I am standing now. Special thanks to Koen, Free, Tom, Wolfgang, Willem, Sven, Gert, Karina, Siegrid, Silke, Brent, Pieter, Nicole and all other colleagues of our department. Lieselotte, Jaël, Valérie and Céline, I am so happy to have met you. I had wonderful times with you, and I hope many others will come. Sara, you are one of my most beautiful encounters. We were colleagues only for a few months but became friends for live.

In addition to my colleagues from the VUB, I also would like to acknowledge all persons involved in the D-SCOPE project. More particularly, thank you to the D-SCOPE research group. Bram, Daan, Ellen, Michaël, Lieve and Anne, the moments spent with you are some of my greatest memories and experiences of my PhD. I also thank the D-SCOPE steering group for all the support and advice.

Additionally, I would like to thank all the organisations I worked with during my PhD as well as all the people who participated in one of the studies of this dissertation.

Besides all the above-mentioned persons from work, I also received a lot of support from my family and friends. In the first place, I would like to thank my family. Mom and dad, I am very grateful to have you as my parents. You always said I could achieve everything I wanted, and you offered me every single opportunity to do so. Thank you for being so supportive, and this every step of the way. Morgane, I know I can count on you if needed. Thank you for always standing by my side. I am also so happy you and Sambou brought Noah in my life. His beauty, smiles and energy gave me the distraction I needed during the last months. Also, many thanks to my other family members (mamy, marainne, Jean-Claude, tonton, Lucy, Emily) as well as my family in law (Siegrid, Guy, Jens, Anja, Johan, An, Jacqueline, Sven, Glen). You were always prepared to help in one way or another.

Furthermore, I would like to thank my friends, especially my 'BBC United Ninove' friends and 'the Sjonnies & Sjakies'. I had great moments of enjoyment and distraction with all of you during these last four years.

And finally, I would like to thank my wonderful fiancé. Gert, you stood by my side from the first day I started university, in 2009. Everything I achieved until now, I owe it to you. You gave me the courage and the confidence to undertake every single encountered challenge. Thank you for being so 'down-to-earth', flexible, generous but also loving, optimistic and enthusiastic. Thank you for being you.

"Now, bring me that horizon!"
Captain Jack Sparrow

Deborah Lambotte
Brussels, October 2018

Table of contents

List of figures

List of tables

Part 1

Introduction

Chapter 1. Introduction

1. Background

1.1. An ageing society

Due to rising life expectancy and declining fertility rates, the share of older adults grows faster than the share of any other age group. As a result, the number of older adults in the total population is increasing. Older adults (60+) in the world are projected to grow by 56% between 2015 and 2030, from 901 million to 1.4 billion (United Nations, 2015). By 2050, the global population of older adults is projected to more than double its size in 2015, reaching almost 2.1 billion. The number of individuals aged 80 years or over, also called 'oldest-old' persons, is growing even faster. By 2050, oldest-old adults will more than triple in number as in 2015.

While population ageing is a global phenomenon, the ageing process is more advanced in some regions than in others. For example, Northern America counted 20.8% older adults (60+) in 2015 while Northern Africa counted 8.0% older adults in 2015 (United Nations, 2015). Europe counted 23.9% older adults (60+) in 2015 (United Nations, 2015). This share will rise to 29.6% by 2030, and to 34.2% by 2050.

In 2016, 18.4% of the Belgian ageing population was 65 years or over, and 5.5% of them was 80 years or over (European Union, 2017). The share of older adults is expected to increase significantly in the coming decades; those aged 65 years or over will account for 24.6% of the Belgian population by 2050. In 2015, women had a greater life expectancy (83.7 years) than men (78.8 years). Women's life expectancy will rise to 88.1 years by 2050, while men's life expectancy will rise to 83.8 years.

1.2. Increasing need for care and support

Older adults grow older but not necessarily in a healthy way. In 2015, the number of healthy life years at birth was estimated at 63 years for women and 62.6 years for men in Europe (Eurostat, 2018). In Belgium, the number of healthy life years at birth was estimated at 64 years for women and 64.4 years for men in Europe. The gender gap is considerably smaller in terms of healthy life years than it is for overall life expectancy.

As individuals age, their risk for health problems and functional limitations increases, which in turn leads to greater frailty and need for care and support. According to De Witte et al. (2016), 22.9% of older adults (60+) in Flanders is severely frail. Belgium is characterised by an increasing rate of severe disability among older adults (Lafortune, Balestat, & the Disability Study Expert Group Members, 2007). The disability prevalence in Belgian older adults (55+) is 35.6% (Yokota et al., 2016). In addition, an increasing number of older adults are living alone and at risk of social isolation (Sundström, Fransson, Malmberg, & Davey, 2009). According to Gerst-Emerson and Jayawardhana (2015), loneliness is associated with higher care use.

The presence of more technological resources, information and communication technologies and improved medical care increase the ability for individuals in need of care and support to live longer at home (Vancea & Solé-Casals, 2016). In this context however, informal and formal caregivers also need to handle more complex care situations (Barrett, Hale, & Butler, 2014).

1.3. Financial unsustainability

The question whether health care systems will be financially sustainable in the future is frequently raised in health policy debates (World Health Organization, 2009). The problem is often phrased in the ability of governments and health care organisations to finance health care in the face of growing cost pressures. Population ageing, new technologies and consumer expectations around health care coverage and quality are the most commonly cited challenges (World Health Organization, 2009).

In Belgium, public spending on long-term care represented 2% of the GDP in 2015 (OECD Health Statistics, 2018), but the demand for long-term care is expected to rise. Conversely, austerity measures have been taken in European health care, like budget cuts in healthcare services, reductions in health coverage and restricting access to care (Stuckler, Reeves, Loopstra, Karanikolos, & McKee, 2017).

1.4. Care network shortages

Governments increasingly rely on informal care to reduce the expensive health care costs (Riedel, 2012). However, the availability of informal care is likely to decrease over the years due to demographic (e.g. reduction in birth rate) and socio-cultural (e.g. increased female participation in the labour force, fragmentation of the traditional family) evolutions (Agree & Glaser, 2009; Ryan, Smith, Antonucci, & Jackson, 2012).

The demographic evolution of the provision of informal care is illustrated with the old-age dependency ratio. The old-age dependency ratio is seen as an indication of the level of support available to older persons by the working-age population and represents the proportion of older adults (65+) to the (potential) working-age population (15-64). The higher the ratio, the lower the level of support available. Figure 1 illustrates the evolution of the old-age dependency ratio for Belgium (World Bank Group, 2018). The old-age dependency ratio has been increasing for a long time. Thirty years ago, there were about five persons of working age for every person aged 65 or over in Belgium. In 2017, this decreased until three persons of working age for every older person.

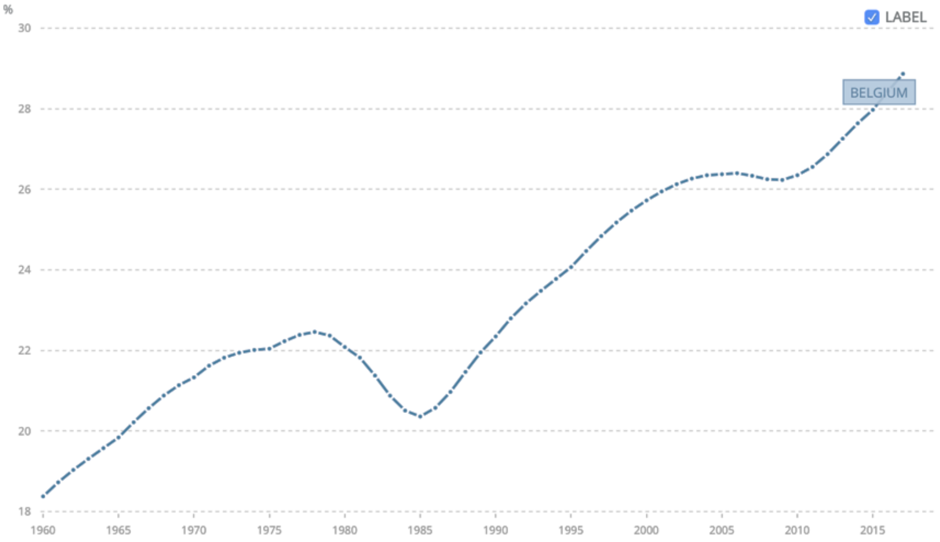


Figure 1. Old-age dependency ratio (World Bank Group, 2018)

One of the most important socio-cultural evolutions is individualisation, whereby the emphasis on autonomy and freedom of choice has increased: "*Being a caregiver no longer seems to be something normal, to be taken for granted in one's trajectory. What appears normal to our respondents is having a professional life, an active social life, and regular activities that allow them to take care of themselves, and this, even if they are caregivers*" (Guberman, Lavoie, Blein, & Olazabal, 2012, p. 216).

In addition to shortages within the provision of informal care, health workforce shortages are predicted as a result of population growth, ageing societies, and the rising demand for healthcare. The European Commission (2012) estimates a potential shortfall of around 1 million health care workers by 2020, rising up to 2 million if long-term care and ancillary professions are taken into account (= 15% of the care and support needed in the EU). The health workforce itself is also ageing with insufficient new recruits to replace those retiring (European Commission, 2012). Additionally, relatively low pay and difficult working circumstances hamper recruiting and retaining staff (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011; European Commission, 2012).

2. Policy frameworks

Aforementioned trends have compelled policymakers and professionals to develop concepts, programs and services to meet the complex and diverse needs of older adults, in particular the segment of older adults who are frail, chronically ill, and functionally disabled (Lecovich, 2014).

2.1. Ageing in place and community care

Ageing in place has become a key and guiding strategy in addressing the needs of older adults. The World Health Organization (2004, p. 9) define ageing-in-place as "*meeting the desire and ability of people, through the provision of appropriate services and assistance, to remain living relatively independently in the community in his or her current home or an appropriate level of housing.*" Older adults themselves have expressed their wish to age in place, to live at home, for as long as possible (Lőfqvist et al., 2013; Smetcoren, 2015; Wiles, Leibing, Guberman, Reeve, & Allen, 2012). When reaching old age, persons become attached to their homes, not only to the physical setting but to the experiences and shared memories embodied in the home (Stones & Gullifer, 2016). The home provides autonomy, privacy and authentic self, and offers a platform for connecting with others as the home allows continuing connectedness with the broader community. Two factors have caused ageing-in-place to emerge as a prominent concern of gerontological policy makers: (1) the explosive growth of homeownership after the Second World War, and (2) the re-emergence of the home as a key site for the provision and consumption of care and support due to the high costs of institutionalisation (cf. community care) (Wiles, 2005).

With governments implementing policies of deinstitutionalisation a shift towards community care occurs (Barrett et al., 2014; Lecovich, 2014). Community care is defined as "*the longer-term care and support for people who are mentally ill, elderly or disabled and which is provided within the community, rather than in hospitals, and which enables individuals to live in both independence and dignity and to avoid social isolation*" (Edmonstone, 2018, p. xvii).

Community care refers to the paradigm shift in which care for older adults becomes less institutionalised, and increasingly becomes the responsibility of society (Means, Richards, & Smith, 2008). This paradigm shift implies that care is provided within the community, as opposed to institutionalisation, and by the community. Increasing importance is hereby given to informal caregivers (i.e. family members, friends, neighbours), in order to compensate for health care budget cuts (Riedel, 2012).

Belgium also has a strong policy focus towards ageing-in-place and community care. The objective to remain at home for as long as possible is present in the Flemish Senior Citizens policy plan 2015-2020 (Flemish Government, 2015). Several actions are therefore taken such as promoting and coordinating housing modifications and developing integrated care and promoting care provision from a network and client-centred perspective. The provision of care and support from informal caregivers and volunteers is encouraged. Within the Flemish Senior Citizens policy plan 2015-2020, informal caregivers and volunteers are seen as the social capital of community care. As a result, a Flemish informal care plan 2016-2020 has been established in order to provide means to value, profess and support these types of caregivers (Vandeurzen, 2016).

2.2. Healthy ageing

Since 2015, the World Health Organization replaced their focus of 'active ageing' with that of 'healthy ageing' as the basis for the lead policy framework (World Health Organization, 2015). Like active ageing, healthy ageing emphasises the need for action across multiple sectors in order to optimise opportunities for physical, psychological and social health and enables older adults to take an active part in society. Rather than focusing on the absence of disease, healthy ageing considers the perspective of the 'functional ability', which enables older adults to be, and to do, what they have reason to value. This functional ability is not only determined by an older individual's intrinsic capacities, but also by the physical and social environments they inhabit.

With regard to care and support, older adults need health care systems that provide integrated and person-centred services, that are located as near as possible to their homes and that deliver care that helps maintain intrinsic capacity for as long as possible (Beard, de Carvalho, Sumi, Officer, & Thiyagarajan, 2017). Since informal caregivers are expected to provide long-term care in many countries, these systems need to support informal caregivers (e.g. through training, home care or respite care) as well in order to enable older adults in need of care and support to live in dignity, while allowing informal caregivers to pursue other aspirations.

2.3. Person-centred and integrated care

Within these evolutions towards deinstitutionalisation and community care, health and social care organisations are challenged to put the wishes and needs of older adults in need of care and support at the forefront. This implies a shift from supply-oriented care to client-driven care (Raak, Mur-Veeman, Hardy, Steenbergen, & Paulus, 2003). In addition, health and social care organisations need to provide sufficient care and support without making care recipients unnecessarily dependent. Rather than a medically oriented approach focusing on professional care, the approach for care and support has become more holistic by strengthening older adults' sense of mastery and supporting them to activate their social network (Penninx & Sprinkhuizen, 2011). This type of care is also referred to as person-centred care (Manley & McCormack, 2008). Key elements of person-centred care are the person's individual needs, expectations, limitations and capacities, and his/her experiences of care (Kardol, 2004; Kitson, Marshall, Bassett, & Zeitz, 2013). The care recipient participates in his/her care and support as a respected and autonomous individual. Person-centred care focusses on the relationship between the care recipient and the formal caregiver, for example by having and maintaining an honest caregiver–care recipient relationship and by using open communication.

Also, in order to overcome the fragmentation of care and a supply-oriented approach, governments are striving for integrated care. Amongst others, frail, older adults have complex needs which often require multiple health care professionals and organisations. Integrated care focuses on the total needs of care recipients, not only on the services provided by one professional or health care organisation (Minkman, 2012). Integrated care has been described as shared care, coordinated care, comprehensive care, etc. and appears in a variety of forms and definitions.

Providing person-centred and integrated care are core components in the Flemish Senior Citizens policy plan 2015-2020 (Flemish Government, 2015). Central in this policy plan regarding the reforms within the health care system are: the reorganisation of formal care (e.g. stimulating intersectoral collaboration, improving alignment, importance of proximity) and the Flemish social protection system (i.e. the package of interventions and financing systems for those who need long-term care and support), strengthening innovative technologies and promoting and supporting informal care. The Flemish Senior Citizens policy plan 2015-2020 uses the circle model as reference framework to support individuals with disabilities, chronically ill individuals and older adults (Flemish Government, 2015). The centre of the model represents the care recipient. The care recipient determines which levels of support can contribute to his health and wellbeing. The focus of the model is his/her self-reliance and the appreciation of informal care. The model follows the principle of subsidiarity and complementarity (as the different support systems build on each other and assistance grows along with the needs of the care recipient) and assumes that the care recipient can switch between the different forms of care according to his evolving needs and wishes.

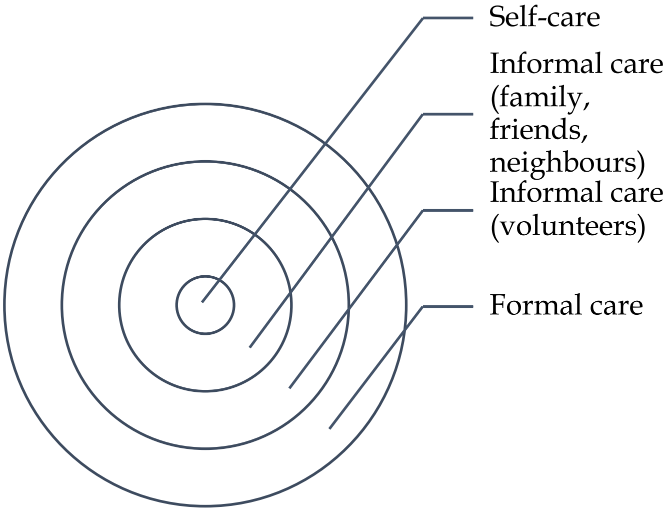


Figure 2. Circle model (Flemish Government, 2015)

Within the Flemish Senior Citizens policy plan 2015-2020, care and support are no longer solely the responsibility of professionals but have become a shared responsibility between care recipients themselves, their social network as well as professionals. Care and support firstly rely on the personal competences and qualities of older care recipients as they are expected to meet their own care needs (Flemish Government, 2015). This strength-based approach stimulates older adults to mobilise their own competences and qualities for as long as possible (Sullivan, 1992). When individuals are not capable to provide self-care, they are expected to appeal to their social network for care and support. For the promotion and support of informal care, the Flemish informal care plan has been developed (Vandeurzen, 2016). This Flemish informal care plan stimulates older adults to access their social network before using formal home care services. Finally, health and social care professionals are increasingly required to take into account individuals' (social) environment.

Within this policy context, a growing consensus emerge that care and support need to be organised and delivered in the local community. As a result, a neighbourhood-oriented care model has been developed as future care model for Flanders and Brussels (Bekaert et al., 2016). This care model strives for the organisation of accessible, available and affordable care and support services at the local level. Neighbourhood-oriented care is a social model which (1) focuses on the wellbeing of all local residents and strengthening social cohesion, (2) stimulates the adaptation of housing and public space in order for individuals to age in place for as long as possible, and (3) joins all forces on the local level to provide the best possible care and support.

3. Towards a comprehensive view on frailty

As a result of changing governmental policies, empowering older adults to age in place and the detection of frailty have become relevant governmental issues (De Witte et al., 2013a). Frailty in older adults is a common research concept (De Witte et al., 2013b). The concept first emerged at the end of the seventies, when the Federal Council on Aging (FCA) in the United States introduced the term 'frail elderly' to describe a specific subpopulation of older adults (De Witte et al., 2013b). Since then, the concept of frailty has been subject of many different approaches and definitions. To date, there is still no consensus about the conceptual definition of frailty (Bergman et al., 2007). This results in great discrepancies in the prevalence of frailty. A systematic review concluded that the prevalence of frailty ranges from 4.0% to 59.1%, depending on its conceptualisation (Collard, Boter, Schoevers, & Oude Voshaar, 2012). However, agreement exists about the importance of frailty. Namely frailty acts as important predictor for adverse health outcomes such as falls, physical limitations, hospitalisation and mortality (Vermeiren et al., 2016), as well as lower levels of wellbeing (Andrew, Fisk, & Rockwood, 2012; Peters, Boter, Buskens, & Slaets, 2012).

The way frailty is conceptualised has important implications for social responses, care practices and personal experiences of care and support (Grenier, 2007). In Europe, the concept of frailty is often linked with discourses on longevity and plays a central role in policy planning and care services delivery (Grenier, 2007; Nicholson, Meyer, Flatley, & Holman, 2013).

3.1. From a unidimensional approach towards a multidimensional approach for frailty

Frailty is often described as a purely biomedical approach. From this perspective, frailty is defined as the collection of biomedical factors which influences a person's psychological state in a way that reduces his/her capacity to withstand environmental stress (Lally & Crome, 2007). The biomedical approach measures frailty as a (clinical) phenotype (Fried et al., 2001) or as an accumulation of health deficits (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013; Etman, Kamphuis, van der Cammen, Burdorf, & van Lenthe, 2015). A wide range of physical problems have been linked to frailty, like weakness, reduced physical activity and weight loss (Fried, Ferrucci, Darer, Williamson, & Anderson, 2004; Romero-Ortuno, Walsh, Lawlor, & Kenny, 2010).

In research, policy and practice, a growing tendency to conceptualise frailty from a multidimensional perspective can be noticed (De Witte et al., 2013a), which is more in line with the experiences and meanings of frailty among older adults themselves (Dury et al., 2008; Grenier, 2007; Warmoth et al., 2016). Namely older adults perceive frailty not only as a physical problem, but also as a psychological, social, cognitive and/or contextual issue. Within multidimensional frailty, different operationalisations exist. For example, Puts, Lips and Deeg (2005) measure frailty by the use of physical functioning and psychological markers such as cognition and depression. The Edmonton Frailty Scale measures social support besides cognition, general health status, functional independence, medication use, nutrition, mood, continence and functional performance (Rolfson, Majumdar, Tsuyuki, Tahir, & Rockwood, 2006). Some other operationalisations aim to be more integrative and comprehend four domains of functioning (the physical, cognitive, psychological and social domain), for example The Tilburg Frailty Indicator (Gobbens, van Assen, Luijkx, Wijnen-Sponselee, & Schols, 2010).

Against the background of an ageing society and ageing in place, the Comprehensive Frailty Assessment Instrument (CFAI) (De Witte et al., 2013c) has been developed to serve as a comprehensive and feasible instrument capable of detecting frail, older adults (De Witte et al., 2013b). This instrument includes all three domains of human functioning (i.e. physical, psychological and social functioning) and the quality of the broader environment in which this functioning takes place. Lately, the cognitive domain has been added to the CFAI, resulting in the CFAI-Plus (De Roeck et al., 2018).

3.2. From a deficit approach towards a strengths-based approach for frailty: frailty balance and positive outcomes

Current literature on frailty often considers frailty as a negative construct, a construct of deficits, while it could also be seen as a more positive concept in two ways (Gobbens, Schols, & van Assen, 2017).

First, the vast majority of research concerning outcomes of frail, older adults focusses on adverse health outcomes such as mortality, functional decline, hospitalisation, institutionalisation, etc. (Vermeiren et al., 2016). However, the inclusion of positive outcomes (e.g. quality of life, sense of mastery, life satisfaction) has proven to be interesting too in relation to frailty in old age (Ament, de Vugt, Verhey, & Kempen, 2014; Dury et al., 2018; van der Vorst, 2017). These studies namely indicate that even frail, older adults might report good levels of wellbeing. For example, Ament and colleagues (2014) indicate that 50% of frail older adults reported a good to excellent quality of life. In another study, 46% of physically frail, older women reported a good quality of life (Zaslavsky et al., 2016).

Second, frailty can be defined as a dynamic process by which individuals react to environmental factors (Nicholson et al., 2013). Based on ideas of Brocklehurst (1973), Rockwood, Fox, Stolee, Robertson and Beattie (1994) conceptualised a dynamic model of frailty which recognises the complex balance of assets and deficits, medical and social, that maintain or threaten a person's independence. One side of the balance are assets (health, functional capacity, social resources, financial resources, etc.) which help individuals to maintain their independence in the community. The other side of the balance are deficits (illness, chronic disease, disability, etc.), which threaten independence. The model is dynamic as it can change in status by adjusting the weights of the various assets and deficits. In line with this perspective, Sipsma (1986) described 'frailty balance' as intervening in the balance between losses and deficits on one side and support and autonomy on the other side. Two individuals with the same frailty profile may have a different frailty balance because the kind of support they need and have on their disposal. For example, van der Vorst et al. (2017) indicate that factors like coping, neighbourhood elements and (in)formal care are important elements for frail, older adults' quality of life. In another study, frail, older participants reported social contacts as the most important factor for their quality of life instead of health, which was reported by non-frail, older adults (Puts et al., 2007). A quantitative study concludes that the financial situation, self-rated health conditions and social networks are important components for frail, older people's life satisfaction (Berglund, Hasson, Wilhelmson, Dunér, & Dahlin-Ivanoff, 2016).

Furthermore, older adults dislike the deficit approach in which an older individual is perceived as someone with (a risk of) deficits (Lette, Baan, van den Berg, & de Bruin, 2015). Older adults prefer receiving support that improves their autonomy and wellbeing instead of interventions focussing on diseases and dysfunctions (Lette et al., 2015; van Kempen et al., 2012). Moreover, individuals labelled as frail by others are more likely to feel frail and behave accordingly (Warmoth et al., 2016). Frailty detection and prevention strategies should adopt a strengths-based approach to identify and reinforce individuals' strengths and resources (Buntinx, Paquay, Fontaine, Ylieff, & De Lepeleire, 2004).

4. Exploring care relationships from a care ethicist perspective

Research on care emerged during the 1970s and 1980s from several concerns of feminist scholars (Fine & Glendinning, 2005). Feminist scholars strived to make visible how care, described as unpaid (invisible) work, was assumed to be naturally provided by women in the private domains of the family and home. Feminist scholars argued that as care at home was considered a women's job, community care policies needed to be understood as regressive and patriarchal, transferring responsibility from the state to the family and ultimately to women. This led to a school focussing on burden of care, which documents various adverse effects resulting from caring to individuals in need of care and support (e.g. Arber, Gilbert, & Evandrou, 1988; Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Hooyman & Gonyea, 1999). Another feminist school emerged in the USA, which rather than emphasising the negative aspects of care, underlines socially positive and desirable components and the relationships in which care is given (Fine & Glendinning, 2005). Namely, the concept of care captures not only the provided care and support services but the relationships between individuals giving and receiving care (Garey, Hansen, Hertz, & MacDonald, 2002). This school conceptualises care as a social and ethical practice.

Such authors on the ethics of care (Held, 2006; Sevenhuijsen, 1998; Tronto, 1993) distance themselves from the conceptualisation of care as a natural, highly personal and private activity undertaken primarily by women and use a relational and context-bound approach. Fisher and Tronto (1990, p. 40) define care as *"a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web"*.

This definition of care contains three components (Tronto, 2001). First, care is described as a 'species' activity, which is a philosophical term that indicates how caring for one another is a typical human activity. Second, care is an action or practice, not a set of principles or rules. Finally, the definition of care contains a flexible standard: the understanding of good care depends upon the set of values and conditions of the individuals engaged in the caring practice. Furthermore, caring is a process that occur in a variety of institutions and settings and thus is not restricted to the traditional view of women's work in the private sphere of the home. Tronto (1993) approaches the care process as an integrated holistic process which contains four elements of care. Each care element needs a moral quality in order to provide 'good care'. The four elements of care (and their moral quality) are caring about (attentiveness), taking care of (responsibility), care-giving (competence) and care-receiving (responsiveness). *Caring about* involves becoming aware or noticing to the need for caring. Caring about requires attentiveness, namely the ability to perceive needs in self and in others. *Caring for* involves the responsibility that someone makes in order to ensure that the identified needs will be met. The moral dimension of caring for is to assume responsibility. *Care-giving* concern the actual caregiving work and requires that individuals/organisations perform the necessary care tasks. Competence is the moral dimension of caregiving. *Care receiving* involves the response of the care recipient, whether the needs have been met or not, whether caregiving was successful or not. Care receiving requires the moral element of responsiveness.

According to Tronto (2001) the care process is complex and rarely occurs in a perfect way. Care is often filled with conflict since there are more care needs than can ever be met. Determining which needs are important inevitably involves ignoring other needs. For example, caregivers have needs at the same time that they give care to others, and they need somehow to balance their needs and those of others. Furthermore, care involves power relations (Tronto, 2001). According to Waerness (1990) many care practices can be defined as necessary because the caregiver has some kind of knowledge or competence that the care recipient does not have. This often results in an imbalance in power among caregivers and care recipients.

5. The provision of informal and formal care to frail, community-dwelling older adults

5.1. The value of informal care

When ageing, older adults are more likely to become frail and dependent for care and support (Gobbens, van Assen, Luijkx, & Schols, 2012). As a result, the demand for both informal and formal care within an ageing society will keep growing (Colombo et al., 2011; Riedel, 2012). Informal care constitutes a significant share of the total long-term care provision in Europe (European Union, 2018). Hoffmann and Rodrigues (2010) estimate that 80% of all long-term care in Europe is provided by informal caregivers. On average, 34.3% of the population in Europe are informal caregivers (Verbakel, Tamlagsrønning, Winstone, Fjær, & Eikemo, 2017). 7.6% of them provide intensive informal care (minimum 11 hours a week). According to the study of Verbakel et al. (2017), Belgium counts 37.9% informal caregivers of which 6.96 % of them provide intensive informal care.

Desmedt and colleagues (2016) estimate the economic value of informal care in Belgium at € 22.27 billion a year. However, informal care is not cost-free either to individuals or to the state (Rodrigues, Schulmann, Schmidt, Kalavrezou, & Matsaganis, 2013). Providing informal care has consequences and the needs of informal caregivers as well as the impact of providing informal care on informal caregivers' employment, health, wellbeing, etc. have to be taken into account in practice and policy (Bouget, Spasova, & Vanhercke, 2016; Brimblecombe, Pickard, King, & Knapp, 2017; Mello et al., 2017). Desmedt et al. (2016) for example estimate that 26,633 informal caregivers are suffering from long-term sickness (i.e. being sick for at least two weeks) as a result of informal care burden, and that the financial impact of informal care on the health insurance pillar in Belgium is € 1.2 million a day. As a result, many countries have included components focused on informal caregivers in their reform packages and informal caregivers are becoming increasingly recognised as full-fledged partners within the care setting of older care recipients (European Union, 2018). The Flemish informal care plan is structured around four chapters (Vandeurzen, 2016). One chapter for instance concerns the collaboration between informal and formal caregivers. The Flemish informal care plan invests amongst others in the awareness-raising among all care providers (informal and formal) of the fact that informal caregivers must be considered as care partners in a well-coordinated care plan, and professional caregivers need to detect the possible care and support needs of informal caregivers as well.

Within the literature, the characteristics and determinants of informal care (Mentzakis, McNamee & Ryan, 2008, Verbakel et al., 2017) and informal caregivers' burden (Mello et al., 2017; Garlo, O'Leary, Van Ness & Fried, 2010; Oldenkamp et al., 2016; Ong et al., 2018) have been thoroughly examined. Researchers tend to focus on family care and find gender differences in patterns of family care as well as differences according to the nature of the relationship (e.g. whether informal care is provided by a spouse or adult child) (Keefe & Fancey, 2002; McGraw & Walker, 2004). A shift in the literature took place on studying informal care as dyads between older adults and individual care providers (Boaz & Hu 1997; Lyons, Zarit, Sayer, & Whitlatch, 2002) towards a focus on care networks (Keating, Otfinowski, Wenger, Fast, & Derksen, 2003) instead. Informal care network members provide different types of care and support tasks, depending on their relationship with the care recipient and to each other (Keating et al., 2003).

Related to this, is the increasing appearance of friends and neighbours as informal caregivers (Kalwij, Pasini, & Wu, 2014; Keating & Dosman, 2009; Lapierre & Keating, 2013; Suanet, van Tilburg, & Broese van Groenou, 2013; van Dijk, Cramm, & Nieboer, 2013). Informal care is often been discussed within the relationship of the family (e.g. Pinquart & Sörensen, 2011; Oldenkamp et al., 2016; Ward-Griffin, 2001; Wolff et al., 2017). However, despite the fact that informal care is often provided by nuclear family members like the spouse and the children, the traditional patterns of care are changing due to the changing structure, nature and roles within the family and societal trends like women's labour force participation (Agree & Glaser, 2009; Ryan et al., 2012). As a result, non-kin care and support is increasingly being recognised as important type of informal care.

5.2. The relationship between informal and formal care

Many frail, community-dwelling older adults receive formal care whether or not in combination to informal care (Denton, Brookman, Zeytinoglu, Plenderleith, & Barken, 2014). Authors underline the need to understand the relationship between both informal and formal care (Geerlings, Pot, Twisk, & Deeg, 2005; Paraponaris, Davin, & Verger, 2012). Several conceptual models for the study of the informal and formal care relationship exist. Four models have received most attention (Ward-Griffin & Marshall, 2003): the hierarchical compensatory model (Cantor, 1979, 1991), the substitution theory (Greene, 1983), the task specificity model (Litwak, 1985) and the complementary model (Chappell & Blandford, 1991).

The *hierarchical compensatory model* focuses on how individuals determine who would be the appropriate person from which to receive support (Cantor, 1979, 1991). Shanas (1979) derived the former model to account for observed regularities in the social support networks of older adults. According to the model, older adults choose for specific caregivers by following a preferred ordering based on the primacy of the relationship between the caregivers and the care recipient. The patterns of care and support follow an orderly hierarchal selection process determined by individuals' preferences for care and support, which are seen as normatively defined and embedded within the cultural values of a society. Within this model, older adults use formal care as last possibility, when care and support from informal caregivers is exhausted. Informal care follows a principle of substitution, with the spouse, children, other family members, friends, neighbours providing care and support in serial order. Limited empirical evidence for the hierarchical compensatory model exist (Cantor, 1983; Chappell, 1991; Penning, 1990).

Similar to the hierarchical compensatory model, the *substitute model* (Greene, 1983) suggest that as formal care is provided, there will be a subsequent decrease in informal care. Empirical evidence for a substitution effect of formal care on informal care is scarce. Like Greene (1983), Stabile, Laporte and Coyte (2006) concluded that when the availability of publicly financed formal home care increases, older adults were more likely to use this type of care and less likely to use informal care. In contrast to these results, several studies highlight the inverse substitute relationship and suggest that informal care substitutes formal care (Bolin, Lindgren, & Lundborg, 2008; Gannon & Davin, 2010; Hanaoka & Norton, 2008; Van Houtven & Norton, 2004). From this perspective older adults who receive informal care are less likely to call upon formal care providers.

The *task specificity model* (Litwak, 1985) argues older adults are more likely to select caregivers to provide care and support if the caregivers have structural features that match those of the required task. So, the structure of the care task determines the source of care rather than older adults' preferences or the availability of informal caregivers. A study from Li, Ji and Chen (2014) supported the task specificity model and found that different types of informal caregivers, assisted with different types of care.

Finally, the *complementary model* (Chappell & Blandford, 1991) acknowledges both compensatory and supplementary functions of formal care. According to the model, formal care supplements informal care when informal care becomes inadequate, or when there is a substantial need for formal care. Supplementation acknowledges that formal care is used in some cases as a replacement for informal care, however it posits that formal care is used by informal caregivers in situations in which they need periodic respite, not permanent relief from their responsibilities. There is empirical evidence for the complementary relationship between informal and formal care (Blomgren, Martikainen, Martelin, & Koskinen, 2008; Bolin et al., 2008; Van Houtven & Norton, 2004).

Those 'conventional' models received several critiques by different scholars. First, these conceptual models treat informal and formal care as two different and separate spheres, rather than potentially overlapping care systems, and assume that informal care is preferred to formal care. Namely the conventional models tend to adopt the traditional perspective of roles within the family, where caregiving is seen as a woman's activity. Ward-Griffin and Marshall (2003) also highlight the absence of wider political, social, and economic contexts and identify structural arrangements, such as gender roles, power relations, the feminisation of care, reduced state funding for home care, and increasing nurse caseloads as keys to understanding formal–informal care intersections. Finally, those models exclude care recipients as potentially active participants in their own care (i.e. self-care), including their roles in care management and supervision, and they do not reflect the dynamic nature of care processes or the increasing complex medical care needs of those with chronic disease and disability (Kemp, Ball, & Perkins, 2013).

5.3. The convoys of care model: a comprehensive approach towards care networks

Within the perspective of aforementioned critiques towards informal and formal care, several authors argue to approach the subject matter from a network perspective and underline the importance of stepping away from a dyadic point of view between both types of care (e.g. Fret et al., 2018; Jacobs et al., 2018; Jacobs, Van Tilburg, Groenewegen, & Broese van Groenou, 2016; Koehly, Ashida, Schafer, & Ludden, 2015). According to Kemp et al. (2013, p. 17) care networks are best conceptualized as "*dynamic and evolving processes that are person- and family-specific, negotiated and influenced by a host of multi-level factors encompassing societal, community, facility and individual levels*". Kemp et al. (2013) developed the *convoy of care model* as an alternative way to conceptualise the intersections between formal and informal care and its relationship to the care recipient and caregiver outcomes. Therefore, they combined different theoretical and conceptual from social gerontology frameworks with Kahn and Antonucci's (1980) convoy model of social relations: the life course perspective (Elder, 1998), feminist gerontology (Calasanti, 2009; Calasanti & Zajicek, 1993), social ecological (Moos, 1979), and symbolic interactionism (Blumer, 1969). Table 1 provides an overview of the theoretical threads and contributions to the convoy of care model by perspective.

Table 1. Theoretical threads and contributions to the convoy of care model by perspective (Kemp et al., 2013)

Convoy model of social relations (Antonucci, 1985; Kahn & Antonucci, 1980)

- Individuals are embedded in convoys, which are dynamic networks of close personal relationships that serve as "*vehicles through which social support is distributed or exchanged*" (Antonucci, 1985, p. 96)
- Evolutionary view of social support: convoy membership and support change over time
- Relationships with convoy members often serve a protective function and provide support (i.e. instrumental care, emotional support and affirmation)
- Convoy properties include *structure* (e.g. size, homogeneity, stability), *function* (e.g. support given, received, exchanged), and *adequacy* (e.g. satisfaction with support) and are influenced by personal (e.g. age, gender, marital status, frailty) and situational(e.g. norms, living situation) characteristics

Life course (Elder, 1998)

- Ageing is a lifelong process
- Focus linked lives: lives are lived interdependently
- Life course changes (transitions, changes in state, and turning points, changes in direction) often affect more than the individual and those surrounding them

Feminist gerontology (Calasanti, 2009; Calasanti & Selvin, 2001; Parks, 2003; Ward-Griffin & Marshall, 2003)

- Relations of inequality are based on gender, race, ethnicity, age, sexuality and social-class position
- One's position in the social structure affects agency, resources and power
- Familism is a pervasice ideology that defines care as a family responsibility and, ultimately, as women's work
- Paid and unpaid care is devalued and marginalised, often rendered invisible
- Introducing *relational autonomy* within care ethics: those involved in the caregiving process, including care recipients and their paid and unpaid caregivers, are connected in ways that are consequential to one another's selves and wellbeing, and all are affected by the political and economic frameworks in which they are embedded
- Older care recipients are not necessarily passive care recipients

Social ecological perspective (Moos, 1979)

- Individuals cannot be divorced from their surrounding environments
- The importance of multiple, intersecting, nested contexts, including societal-, community-, institutional-, and individual-level factors

Symbolic interactionst perspective (Blumer, 1969)

- Meaning and interpretation is central within action and interaction
- Care is a process that is "negotiated" or worked out over time

The convoy of care model (Kemp et al., 2013) suggests an evolutionary collaboration of care partners involving both formal and informal caregivers and their care recipients. Kemp et al. (2013, p. 18) define convoys of care as "*the evolving collection of individuals who may or may not have close personal connections to the recipient or to one another, but who provide care, including help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), socio-emotional care, skilled health care, monitoring, and advocacy.*"

Each care convoy has properties unique in structure and function, both of which can influence its adequacy. Who does what in individual care convoys generally changes over time through negotiation. Care convoys and negotiations are influenced by factors at the societal, community, care industry, care setting, formal–informal network, and individual levels. Care convoys have outcomes for self and identity, which are intimately connected to care recipients' ability to age in place and wellbeing, as well as for informal caregivers' sense of fulfilling family responsibility, satisfaction with care and levels of care burden, and formal care workers' job satisfaction.

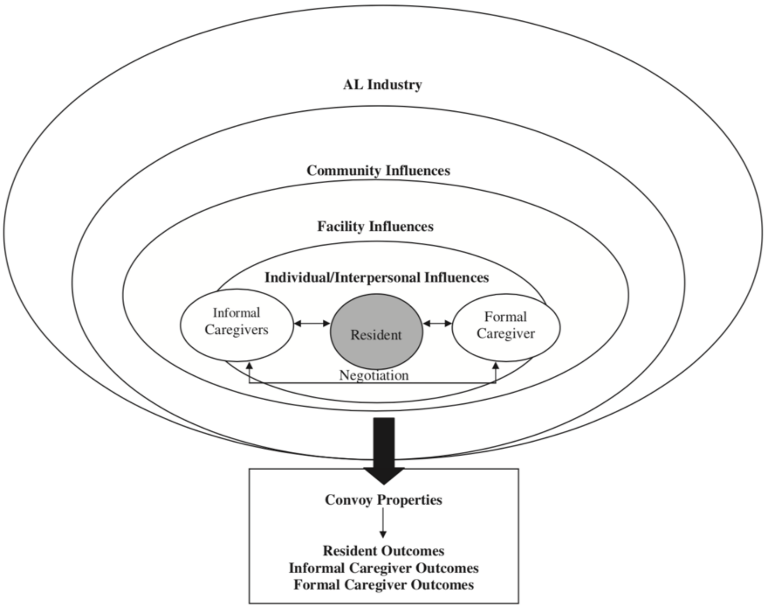


Figure 3. The convoys of care model (Kemp et al., 2013)

6. Research gaps

Although previous research within the field of social gerontology has contributed significantly to our understanding of (in)formal care of frail, older adults, a number of remaining research gaps can be identified.

A first research gap regards the multidimensionality of frailty. Despite the growing tendency to approach frailty from a multidimensional perspective (e.g. De Roeck et al., 2018; Gobbens et al., 2010; Grenier, 2007), only a few empirical studies use this multidimensional approach for frailty in relation to (in)formal care (e.g. Jacobs et al., 2016; Janse, Huijsman, Looman, & Fabbricotti, 2018; Verver, Merten, Robben, & Wagner, 2018). Using a multidimensional approach for frailty in older adults permits to explore broader care needs, not only on physical matters but also on cognitive, psychological, social and environmental issues.

A second research gap regards the narrow approach towards (in)formal care and support. Studies in general focus on one central informal – formal caregiver dyad (Bell & Rutherford, 2013; Byrne, Goeree, Hiedemann, & Stern, 2009; Kruijswijk, Da Roit, & Hoogenboom, 2014). As a result, the presence of multiple informal and formal caregivers is ignored. However, several types of informal care (e.g. family caregivers, friends, neighbours) (Kalwij et al., 2014; Keating & Dosman, 2009) as well as formal care (e.g. home nurse, meals-on-wheels-, general practitioner) (Hoeck et al., 2011) exist. Within this perspective, authors suggest approaching informal and formal care from a network perspective (Keating et al., 2003; Koehly et al., 2015). To date, little empirical evidence exists concerning care networks of older adults (Verver et al., 2018). Kemp et al. (2013) propose to use the convoy of care model in order to understand care networks of frail, older adults. Despite its applicability across care settings, the convoy of care model has only been illustrated within assisted-living settings (Kemp et al., 2013, 2017, 2018). Furthermore, studies need to explore relational and social aspects of care (Barnes, 2012). By the use of an ethics of care, the interconnectedness between caregivers and care recipients within care relationships is acknowledged (Fine & Glendinning, 2005). Research and policy often use a fixed, one-directional view of the relationship between caregiving and care receiving, which fails to account for the complex, interpersonal and reciprocal nature of care and support (Henderson & Forbat, 2002; Lloyd, 2000; Sims-Gould & Martin-Matthews, 2010).

Finally, the third gap regards the lack of attention to the frailty-balance and positive outcomes (Dury et al., 2018). Although frailty is often interpreted as a negative construct, studies point towards the dynamic state of frailty (cf. frailty balance) (Gobbens et al., 2017; Rockwood et al., 1994). Older adults can experience less or no negative consequences from their frailty and high levels of wellbeing by the use/presence of strengths and resources (Dury et al., 2018; van der Vorst et al., 2017). Within older adults' positive outcomes and frailty balance, informal and formal care may be of great importance.

Chapter 2. Aims and outline of the dissertation

1. Research framework

The central objective of this dissertation is to contribute to the literature about the dynamics of care networks of frail, older adults. More specifically, this dissertation investigates how care convoys serve as protective factor for wellbeing in frail, community-dwelling older adults. The different components of this dissertation are visualised in Figure 4.

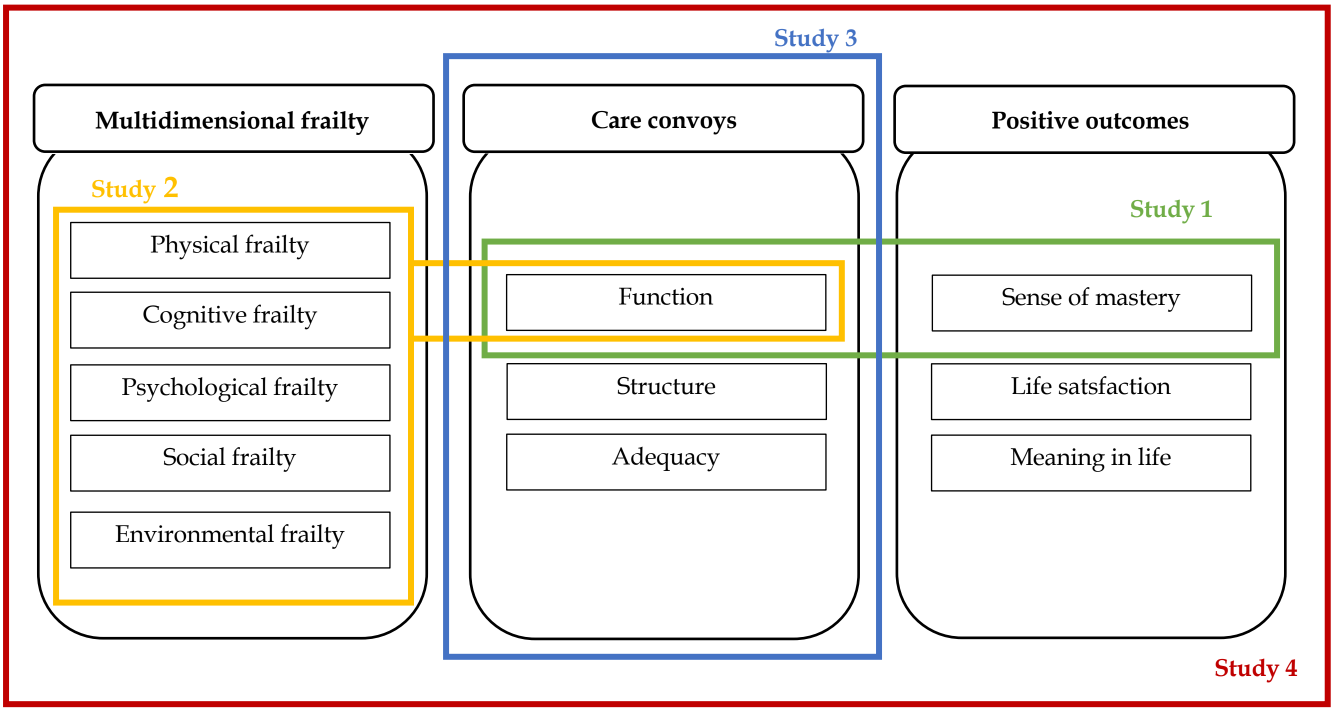


Figure 4. Overview of the dissertation

By the use of a multidimensional approach for frailty (De Roeck et al., 2018; De Witte et al., 2013), an ethics of care perspective (Tronto, 1993) and the convoy of care model (Kemp et al., 2013), this dissertation contributes to a comprehensive view of care relationships and broader care needs of frail, community-dwelling older adults. The dissertation includes three research goals:

1) Exploring the positive outcomes in frail, community-dwelling older care recipients
2) Exploring the meaning and added value of broadening the view on care and support by the use of the convoy of care model in frail, community-dwellings older adults
3) Exploring care convoys as balancing factor for frail, community-dwellings older adults' wellbeing

2. Outline of the dissertation

This dissertation is divided in four parts, containing nine chapters. *Part 1* presents a general introduction, in which the rationale behind studying care networks of frail, community older adults is illustrated (**chapter 1**). Chapter 1 contains a description of the demographic evolution of population ageing and its consequences for care networks, policy frameworks related to care and support, frailty (balance) literature, theoretical frameworks relevant for this dissertation and an overview of the informal and formal care literature. Subsequently, research gaps are formulated and discussed. **Chapter 2** provides the dissertation's framework, objectives and outline of the dissertation.

Part 2 provides a description of the methodology and data used in the different empirical studies (**chapter 3**). Data from two research projects are used: quantitative data from the Belgian Ageing Studies (N = 38,066), and qualitative data (N = 65) as well as quantitative data (N = 619) from the Detection, Support and Care for Older people: Prevention and Empowerment (D-SCOPE) project. The latter originates from the D-SCOPE frailty program, a longitudinal randomised four-armed controlled trial with follow-up at 6 months, of which the protocol can be found in **chapter 4**.

Part 3 contains the four studies related to care convoys of frail, community-dwelling older adults. Because of the importance given to the stimulation of older adults' mastery in policy and practice, and the particularity of the relationship between older care recipients and informal caregivers, **chapter 5** explores how frail, community-dwelling older adults experience relational aspects of mastery and the role of their informal caregivers in maintaining these aspects of mastery over the care process, as defined by Tronto (1993). A secondary analysis of 65 interviews with frail, community-dwelling older adults who participated in the D-SCOPE project is performed in order to gain insights into relational aspects of frail, older adults' mastery (study 1).

As frail, community-dwelling older adults often receive formal care in addition to informal care, **Chapter 6** examines the relationship between the structure of care convoy and multidimensional frailty among community-dwelling older adults in Flanders and Brussels (N = 38,066), using data from the Belgian Ageing Studies. Frailty is explored based on the model of health care services uses (Andersen & Newman, 2005); as a need for care (physical and psychological frailty) and enabling factors for care use (social and environmental frailty). Insights are provided with regard to the use of multiple types of informal and formal caregivers among community-dwelling older adults and frailty influences in the use of different combinations of informal and formal care (study 2).

Based on the convoy of care model (Kemp et al., 2013), **chapter 7** provides insights into the complex interplay between care recipients, informal caregivers and formal caregivers, and the dynamicity of care convoys of frail, community-dwelling older adults. A secondary analysis of 65 interviews is performed concerning frail, older adults' meaning and experiences of their care convoy (study 3).

Chapter 8 explores how care convoy properties (i.e. structure, function and adequacy of care convoys) moderate the relationship between frailty (i.e. physical, cognitive psychological, social and environmental frailty) and wellbeing (i.e. sense of mastery, meaning in life and life satisfaction) among community-dwelling older care recipients (N = 619). The data originates from the T0 data of the D-SCOPE frailty program (study 4).

Part 4 regards the general discussion of the dissertation (**chapter 9)**. In this chapter, the different research objectives specified in the first chapter are discussed. Based on the key findings, suggestions for policy and practice are formulated. Finally, a critical appraisal of the limitations of the dissertation as well as recommendations for future research are formulated.

Table 2 provides an overview of the studies included. The studies are developed as stand-alone articles, which may cause some overlapping within the chapters.

Table 2. Overview of article included in this dissertation.

	Type of study	**Population**	**Origin of the data**	**Publication status**
Chapter 4. Randomized controlled trial to evaluate a prevention program for frail community- dwelling older adults: a D-SCOPE protocol	Protocol	Community-dwelling older adults at risk for frailty	Third research phase of the D-SCOPE project (D-SCOPE frailty program; Lambotte et al., 2018)	*Accepted: August 2018* BMC Geriatrics
Chapter 5. Relational aspects of mastery for frail, older adults: The role of informal caregivers in the care process	Qualitative study	Frail, older adults receiving (at least) informal care (N = 65)	Second research phase of the D-SCOPE project (Dury et al., 2018)	*Accepted: September 2018* Health and Social Care in the Community
Chapter 6. Frailty differences in older adults' use of informal and formal care	Cross-sectional study	Community-dwelling older adults (N = 38,066)	Belgian Ageing Studies project (De Donder et al., 2014)	*Accepted: August 2018* Archives of Gerontology and Geriatrics
Chapter 7. Meanings of care convoys: The structure, function and adequacy of care networks among frail, community-dwelling older adults	Qualitative study	Frail, older adults receiving (at least) informal care (N = 65)	Second research phase of the D-SCOPE project (Dury et al., 2018)	*Submitted*
Chapter 8. Wellbeing and frailty of community-dwelling older adults: The moderating role of care convoys	Cross-sectional study	Older care recipients at risk for frailty (N = 619)	Third research phase of the D-SCOPE project (D-SCOPE frailty program; Lambotte et al., 2018)	*Submitted*

References

Agree, E. M., & Glaser, K. (2009). Demography of informal caregiving. In P. Uhlenberg (Ed.), *International handbook of population aging* (pp. 647-668). New York: Springer.

Ament, B. H. L., de Vugt, M. E., Verhey, F. R. J., & Kempen, G. I. J. M. (2014). Are physically frail older persons more at risk of adverse outcomes if they also suffer from cognitive, social, and psychological frailty? *European Journal of Ageing*, *11*(3), 213–219. doi: 10.1007/s10433-014-0308-x

Andersen, R., & Newman, J. F. (2005). Societal and individual determinants of medical care utilization in the United States. *The Milbank Memorial Fund Quarterly: Health and Society*, *51*(1), 95-124. doi: 10.1111/j.1468-0009.2005.00428.x

Andrew, M. K., Fisk, J. D., & Rockwood, K. (2012). Psychological well-being in relation to frailty: a frailty identity crisis? *International Psychogeriatrics*, *24*(8), 1347-1353. doi: 10.1017/S1041610212000269

Antonucci, T. C. (1985). Personal characteristics, social support and social behavior. In R. H. Binstock & E. Shanas (Eds.), *Handbook of aging and the social sciences.* (pp. 94–128). New York: Van Nostrand.

Arber, S., Gilbert, N., & Evandrou, M. (1988). Gender, household composition and receipt of domiciliary services by elderly disabled people. *Journal of Social Policy*, *17*(2), 153-175. doi: 10.1017/S0047279400016615

Barnes, M. (2012). *Care in everyday life. An ethic of care in practice*. Bristol: Policy Press.

Barrett, P., Hale, B., & Butler, M. (2014). *Family care and social capital: Transitions in informal care*. Dordrecht: Springer Science + Business Media.

Beard, J. R., de Carvalho, I. A., Sumi, Y., Officer, A., & Thiyagarajan, J., A. (2017). Healthy ageing: Moving forward. *Bulletin World Health Organization*, *95*, 730-730A. doi: 10.2471/BLT.17.203745

Bekaert, A., Denys, B., De Muynck, J., De Vriendt, T., Foriers, L., Moonsn S., et al. (2016). *Buurtgerichte zorg. De actief zorgzame buurt als toekomstmodel voor Vlaanderen en Brussel*. Brussel: VVDC & Kenniscentrum Woonzorg Brussel.

Bell, D., & Rutherford, A. (2013). Individual and geographic factors in the formation of care networks in the UK. *Population, Space and Place*, *19*(6), 727-737. doi: 10.1002/psp.1792

Berglund, H., Hasson, H., Wilhelmson, K., Dunér, A., & Dahlin-Ivanoff, S. (2016). The impact of socioeconomic conditions, social networks, and health on frail older people's life satisfaction: A cross-sectional study. *Health Psychology Research*, *4*(1), 5578. doi: 10.4081/hpr.2016.5578

Bergman, H., Ferrucci, L., Guralnik, J., Hogan, D. B., Hummel, S., Karunananthan, S., et al. (2007). Frailty: An emerging research and clinical paradigm – Issues and controversies. *The Journals of Gerontology: Series A*, *62*(7), 731-737. doi: 10.1093/gerona/62.7.731

Blomgren, J., Martikainen, P., Martelin, T., & Koskinen, S. (2008). Determinants of home-based formal help in community-dwelling older people in Finland. *European Journal of Ageing*, *5*(4), 335–347. doi: 10.1007/s10433-008-0094-4

Blumer, H. (1969). *Symbolic interaction: Perspective and method*. Englewood Cliffs, NJ: Prentice Hall.

Boaz, R. F., & Hu, J. (1997). Determining the amount of help used by disabled elderly persons at home: The role of coping resources. *The Journals of Gerontology: Series B*, *52B*(6), S317-S324. doi: 10.1093/geronb/52B.6.S317

Bolin, K., Lindgren, B., & Lundborg, P. (2008). Informal and formal care among single-living elderly in Europe. *Health Economics*, *17*(3), 393-409. doi: 10.1002/ hec.1275

Bouget, D., Spasova, S., & Vanhercke, B. (2016). *Work-life balance measures for persons of working age with dependent relatives in Europe. A study of national policies*. Brussels: European Commission.

Brimblecombe, N., Pickard, L., King, D., & Knapp, M. (2017). Perceptions of unmet needs for community social care services in England. A comparison of working carers and the people they care for. *Health and Social Care in the Community*, *25*(2), 435-446. doi: 10.1111/hsc.12323

Brocklehurst, J. C. (1973). *Textbook of geriatric medicine and gerontology*. London: Churchill.

Buntinx, F., Paquay, L., Fontaine, O., Ylieff, M., & De Lepeleire, J. (2004). Options For a new procedure for determining care needs in Belgium: an initial exploration. *Archives of Public Health*, *62*(3-4), 173–184.

Byrne, D., Goeree, M. S., Hiedemann, B., & Stern, S. (2009). Formal home health care, informal care, and family decision-making. *International Economic Review*, *50*(4), 1205-1242. doi: 10.1111/j.1468-2354.2009.00566.x.

Calasanti, T. (2009). Theorizing feminist gerontology, sexuality, and beyond: An intersectional approach. In V. L. Bengtson, M. Silverstein, M. M. Putney & M. Gans (Eds.), *Handbook of theories of aging* (pp. 471–485). New York: Springer.

Calasanti, T. M., & Zajicek, A. M. (1993). A socialist-feminist approach to aging: Embracing diversity. *Journal of Aging Studies*, *7*(2), 117–131. doi: 10.1016/0890-4065(93)90029-J

Cantor, M. H. (1979). Neighbors and friends: An overlooked resource in the informal support system. *Research on Aging*, *1*(4), 434-463. doi: 10.1177/016402757914002

Cantor, M. H. (1983). Strain among caregivers: a study of experience in the United States. *The Gerontologist*, *23*(6), 597-604. doi: 10.1093/geront/23.6.597

Cantor, M. H. (1991). Family and community: Changing roles in an aging society. *The Gerontologist*, *31*(3), 337-346. doi: 10.1093/geront/31.3.337

Chappell, N. L. (1991). In-group differences among elders living with friends and family other than spouse. *Journal of Aging Studies*, *5*(1), 61–76. doi: 10.1016/0890-4065(91)90025-N

Chappell, N., & Blandford, A. (1991). Informal and formal care: Exploring the complementarity. *Ageing & Society*, *11*(3), 299–317. doi: 10.1017/S0144686X00004189

Clegg, A., Young, J., Iliffe, S., Rikkert, M. O., & Rockwood, K. (2013). Frailty in older people. *Lancet*, *381*(9868), 752-762. doi: 10.1016/S0140-6736(12)62167-9

Collard, R. M., Boter, H., Schoevers, R. A., & Oude Voshaar, R. C. (2012). Prevalence of frailty in community-dwelling older persons: A systematic review. *Journal of the American Geriatrics Society*, *60*(8), 1487-1492. doi: 10.1111/j.1532-5415.2012.04054.x

Colombo, F., Llena-Nozal, A., Mercier, J., & Tjadens, F. (2011). *Help wanted? Providing and paying for long-term care*. Paris: OECD Health Policy Studies, OECD Publishing.

De Donder, L., De Witte, N., Verté, D., Dury, S., Buffel, T., Smetcoren, A.-S., et al. (2014). Developing evidence-based age-Friendly policies: A participatory research project. *Research Methods Cases*. London: SAGE. doi: 10.4135/978144627305013508507

Denton, M., Brookman, C., Zeytinoglu, I., Plenderleith, J., & Barken, R. (2014). Task shifting in the provision of home and social care in Ontario, Canada: Implications for quality of care. *Health and Social Care in the Community*, *23*(5), 485-492. doi: 10.1111/hsc.12168

De Roeck, E. E., Dury, S., De Witte, N., De Donder, L., Bjerke, M., De Deyn, P. P., et al. (2018). CFAI-Plus: Adding cognitive frailty as a new domain to the comprehensive frailty assessment instrument. *International Journal of Geriatric Psychiatry, 33*(7), 941-947. doi: 10.1002/gps.4875

Desmedt, M., Bergs, J., Vertriest, S., Hellings, J., Petrovic, M., & Vandijck, D. (2016). *De economische waarde van mantelzorg en de financiële impact ervan op de ziekteverzekering*. Retrieved on 27 September 2018, from https://uhdspace.uhasselt.be/dspace/bitstream/1942/21765/1/Mantelzorg.pdf

De Witte, N., Campens, J., De Donder, L., Dierckx, E., Rammelaere, S., & Verté, D. (2016). Oudere mensen blijven langer thuis wonen. Zicht krijgen op kwetsbare groepen wordt belangrijk *Sociaal.Net*. Retrieved on 27 September 2018, from https://sociaal.net/analyse-xl/oudere-mensen-blijven-langer-thuis-wonen/

De Witte, N., De Donder, L., Dury, S., Buffel, T., Verté, D., & Schols, J. (2013b). A theoretical perspective on the conceptualisation and usefulness of frailty and vulnerability measurements in community dwelling older persons. *Aporia: The Nursing Journal*, *5*(1), 13-31.

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Schols, J., et al. (2013a). The Comprehensive Frailty Assessment Instrument: Development, validity and reliability. *Geriatric Nursing*, *34*(4), 274-281. doi: 10.1016/j.gerinurse.2013.03.002

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Verté, D., et al. (2013c). Validation of the Comprehensive Frailty Assessment Instrument against the Tilburg Frailty Indicator. *European Geriatric Medicine*, *4*(4), 248-254. doi: 10.1016/j.eurger.2013.03.001

Dury, S., Dierckx, E., van der Vorst, A., Van der Elst, M., Fret, B., Duppen, D., et al. (2018). Detecting frail, older adults and identifying their strengths: results of a mixed-methods study. *BMC Public Health*, *18*, 191. doi: 10.1186/s12889-018-5088-3

Edmonstone, J. (2018). *Action learning in health, social and community care. Principles, practices and resources*. Boca Raton, Florida: CRC Press, Taylor & Francis Group.

Elder, G. H., Jr. (1998). The life course and human development. In R. M. Lerner (Ed.), *Handbook of child psychology: Theoretical models of human development, Volume 1* (pp. 939–991). New York: Wiley and Sons.

Etman, A., Kamphuis, C. B. M., van der Cammen, T. J. M., Burdorf, A., & van Lenthe, F. J. (2015). Do lifestyle, health and social participation mediate educational inequalities in frailty worsening? *European Journal of Public Health*, *25*(2), 345-350. doi: 10.1093/eurpub/cku093

European Commission. (2012). *Commission staff working document on an action plan for the EU health workforce. Accompanying the document communication from the Commission to the European*

Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. Retrieved on 27 September 2018, from https://ec.europa.eu/health/sites/health/files/workforce/docs/staff_working_doc_healthcare_workforce_en.pdf

European Union. (2017). *The 2018 ageing report. Underlying assumptions & projection mythologies*. Luxembourg: Publications Office of the European Union.

European Union. (2018). *Informal care in Europe. Exploring formalisation, availability and quality*. Luxembourg: Publications Office of the European Union.

Eurostat. (2018). *Healthy life years statistics*. Retrieved on 27 September 2018, from http://ec.europa.eu/eurostat/statistics-explained/index.php/Healthy_life_years_statistics

Flemish Government. (2015). *Vlaams Ouderenbeleidsplan 2015-2020*. Retrieved on 27 September 2018, from https://www.vlaanderen.be/en/nbwa-news-message-document/document/09013557801b11b5

Fine, M., & Glendinning, C. (2005). Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing & Society*, *25*(4), 601-621. doi: 10.1017/S0144686X05003600

Fisher, B., & Tronto, J. (1990). Toward a feminist theory of caring. In E. K. Abel & M. K. Nelson (Eds.), *Circles of care. Work and identity in women's lives* (pp. 35-59). Albany: State University of New York Press.

Fret, B., Lambotte, D., Van Regenmortel, S., Dury, S., De Witte, N., Dierckx, E., et al. (2017). Socio-demographic, socio-economic and health need differences between types of care use in community-dwelling older adults. *International Journal of Care and Caring*, *1*(3), 351-366. doi: 10.1332/239788217X15027193795897

Fried, L. P., Ferrucci, L., Darer, J., Williamson, J. D., & Anderson, G. (2004). Untangling the concepts of disability, frailty, and comorbidity: Implications for improved targeting and care. *The Journals of Gerontology: Series A*, *59*(3), M255–M263. doi: 10.1093/gerona/59.3.M255

Fried, L. P., Tangen, C. M., Walston, J., Newman, A. B., Hirsh, C., Gottdiener, J., et al. (2001). Frailty in older adults: Evidence for a phenotype. *The Journals of Gerontology: Series A*, *56*(3), M146–M157. doi: 10.1093/gerona/56.3.M146

Gallicchio, L., Siddiqi, N., Langenberg, P., & Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *International Journal of Geriatric Psychiatry*, *17*(2), 154-163. doi: 10.1002/gps.538

Gannon, B., & Davin, B. (2010). Use of formal and informal care services among older people in Ireland and France. *European Journal of Health Economics, 11*(5), 499-511. doi: 10.1007/s10198-010-0247-1

Garey, A. I., Hansen, K. V., Hertz, R., & MacDonald, C. (2002). Care and kinship: An introduction. *Journal of Family Issues*, *23*(6), 703-715.

Garlo, K., O'Leary, J. R., Van Ness, P. H., & Fried, T. R. (2010). Burden in caregivers of older adults with advanced illness. *Journal of the American Geriatrics Society*, *58*(12), 2315-2322. doi: 10.1111/j.1532-5415.2010.03177.x

Geerlings, S. W., Pot, A. M., Twisk, J. W. R., & Deeg, D. J. H. (2005). Predicting transitions in the use of informal and professional care by older adults. *Ageing & Society*, *25*(1), 111–130. doi: 10.1017/S0144686X04002740

Gerst-Emerson, K., & Jayawardhana, J. (2015). Loneliness as a public health issue: The impact of loneliness on health care utilisation among older adults. *American Journal of Public Health*, *105*(5), 1013-1019. doi: 10.2105/AJPH.2014.302427

Gobbens, R. J. J., Schols, J. M. G. A., & van Assen, M. A. L. M. (2017). Exploring the efficiency of the Tilburg Frailty Indicator: A review. *Clinical Interventions in Aging*, *12*, 1739-1752. doi: 10.2147/CIA.S130686

Gobbens, R. J. J., van Assen, M. A. L. M., Luijkx, K. G., & Schols, J. M. G. A. (2012). The predictive validity of the Tilburg Frailty Indicator: Disability, health care utilization, and quality of life in a population at risk. *The Gerontologist*, *52*(5), 619–631. doi: 10.1093/geront/gnr135

Gobbens, R. J. J., van Assen, M. A. L. M., Luijkx, K. G., Wijnen-Sponselee, M. Th., & Schols, J. M. G. A. (2010). The Tilburg Frailty Indicator: Psychometric properties. *Journal of the American Medical Directors Association*, *11*(5), 344-355. doi: 10.1016/j.jamda.2009.11.003

Greene, V. L. (1983). Substitution between formally and informally provided care for the impaired elderly in the community. *Medical Care*, *21*(6), 609–619.

Grenier, A. (2007). Constructions of frailty in the English language, care practice and the lived experience. *Ageing & Society*, *27*(3), 425-445. doi: 10.1017/S0144686X06005782

Guberman, N., Lavoie, J., Blein, L., & Olazabal, I. (2012). Baby boom caregivers: Care in the age of individualization. *The Gerontologist*, *52*(2), 210-218. doi: 10.1093/geront/gnr140

Hanaoka, C., & Norton, E. C. (2008). Informal and formal care for elderly persons: How adult children's characteristics affect the use of formal care in Japan. *Social Science & Medicine*, *67*(6), 1002–1008. doi: 10.1016/j.socscimed.2008.05.006

Held, V. (2006). *The ethics of care: Personal, political, and global*. Oxford: University Press, Inc.

Henderson, J., & Forbat, L. (2002). Relationship-based social policy: Personal and policy constructions of 'care'. *Critical Social Policy*, *22*(4), 669–687. doi: 10.1177/026101830202200406O1

Hoeck, S., François, G., Geerts, J., Van der Heyden, J., Vandewoude, M., & Van Hal, G. (2011). Health-care and home-care utilization among frail elderly persons in Belgium. *European Journal of Public Health*, *22*(5), 671-676. doi: 10.1093/eurpub/ckr133

Hoffmann, F., & Rodrigues, R. (2010). *Informal carers: Who takes care of them?* Retrieved on 27 September 2018, from https://www.euro.centre.org/publications/detail/387

Hooyman, N. R., & Gonyea, J. G. (1999). A feminist model of family care: Practice and policy directions. *Journal of Women & Aging*, *11*(2-3), 149-169.

Jacobs, M. T., Broese van Groenou, M. I., Aartsen, M. J., & Deeg, D. J. H. (2018). Diversity in older adults' care networks: The added value of individual beliefs and social network proximity. *The Journals of Gerontology: Series B*, *73*(2), 326-336, doi: 10.1093/geronb/gbw012

Jacobs, M., Van Tilburg, T., Groenewegen, P., & Broese van Groenou, M. (2016). Linkages between informal and formal care-givers in home-care networks of frail older adults. *Ageing & Society*, *36*(8), 1604-1624. doi: 10.1017/ S0144686X15000598

Janse, B., Huijsman, R., Looman, W. M., & Fabbricotti, I. N. (2018). Formal and informal care for community-dwelling frail elderly people over time: A comparison of integrated and usual care in the Netherlands. *Health and Social Care in the Community*, *26*(2), e280-e290. doi: 10.1111/hsc.12516

Kahn, R. L., & Antonucci, T. C. (1980). Convoys over the life course: A life course approach. In P. B. Baltes, & O. Brim (Eds.), *Life span development and behavior* (pp. 253–286). New York: Academic Press.

Kalwij, A., Pasini, G., & Wu, M. (2014). Home care for the elderly: the role of relatives, friends and neighbors. *Review of Economics of the Household*, *12*(2), 379-404. doi: 10.1007/s11150-012-9159-4

Kardol, M. J. M. (2004). *Zorg voor zelfstandigheid. Verslag van een studie over de zorg voor zelfstandigheid in verzorgingshuizen en het bevorderen van die zorg* (Doctoral dissertation). Tilburg: Gianotten B. V.

Keating, N., & Dosman, D. (2009). Social capital and the care networks of frail seniors. *Canadian Review of Sociology*, *46*(4), 301-318. doi: 10.1111/j.1755-618X.2009.01216.x

Keating, N., Otfinowski, P., Wenger, C., Fast, J., & Derksen, L. (2003). Understanding the caring capacity of informal networks of frail seniors: A case for care networks. *Ageing & Society*, *23*(1), 115-127. doi: 10.1017/S0144686X02008954

Keefe, J. M., & Fancey, P. J. (2002). Work and eldercare: Reciprocity between older mothers and their employed daughters. *Canadian Journal on Aging*, *21*(2), 229-241. doi: 10.1017/S0714980800001495

Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: Theorizing intersections of formal and informal care. *Journal of Aging Studies*, *27*(1), 15-29. doi: 10.1016/j.jaging.2012.10.002

Kemp, C. L., Ball, M. M., Morgan, J. C., Doyle, P. J., Burgess, E. O., Dillard, J. A., et al. (2017). Exposing the backstage: Critical reflections on a longitudinal qualitative study of residents' care networks in assisted living. *Qualitative Health Research*, *27*(8), 1190-1202. doi: 10.1177/1049732316668817

Kemp, C. L., Ball, M. M., Morgan, J. C., Doyle, P. J., Burgess, E. O., & Perkins, M. M. (2018). Maneuvering together, apart, and at odds: Residents' care convoys in assisted living. *Journals of Gerontology, Series B*, *73*(4), e13-e23. doi: 10.1093/geronb/gbx184

Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing*, *69*(1), 4-15. doi: 10.1111/j.1365-2648.2012.06064.x

Koehly, L. M., Ashida, S., Schafer, E. J., & Ludden, A. (2015). Caregiving networks – Using a network approach to identify missed opportunities. *Journals of Gerontology: Series B*, *70*(1), 143-154. doi: 10.1093/geronb/gbu111

Kruijswijk, W., Da Roit, B., & Hoogenboom, M. (2015). Elasticity of care networks and the gendered division of care. *Ageing & Society*, *35*(4), 675-703. doi: 10.1017/S0144686X13000822

Lafortune, G., Balestat, G., & the Disability Study Expert Group Members. (2007). *OECD health working papers no. 26. Trends in severe disability among elderly people: Assessing the evidence in 12 OECD countries and the future implications*. Retrieved on 27 September 2018, from http://www.oecd.org/els/soc/38343783.pdf

Lally, F., & Crome, P. (2007). Understanding frailty. *Postgraduate Medical Journal*, *83*(975), 16-20. doi: 10.1136/pgmj.2006.048587

Lambotte, D., De Donder, L., De Roeck, E. E., Hoeyberghs, L. J., van der Vorst, A., Duppen, D., et al. (2018). Randomized controlled trial to evaluate a prevention program for frail community- dwelling older adults: a D-SCOPE protocol. *BMC Geriatrics*, *18*, 194. doi: 10.1186/s12877-018-0875-3

Lapierre, T. A., & Keating, N. (2013). Characteristics and contributions of non-kin carers of older people: a closer look at friends and neighbours. *Ageing & Society*, *33*(8), 1442-1468. doi: 10.1017/S0144686X12000736

Lecovich, E. (2014). Aging in place: From theory to practice. *Anthropological notebooks*, *20*(1), 21-33.

Lette, M., Baan, C. A., van den Berg, M., & de Bruin, S. R. (2015). Initiatives on early detection and intervention to proactively identify health and social problems in older people: experiences from the Netherlands. *BMC Geriatrics*, *15*, 143. doi: 10.1186/s12877-015-0131-z

Li, H., Ji, Y., & Chen, T. (2014). The roles of different sources of social support on emotional wellbeing among Chinese elderly. *PLoS ONE*, *9*(3), e90051. doi: 10.1371/journal.pone.0090051

Litwak, E. (1985). *Helping the elderly: the complementary roles of informal networks and formal systems*. New York: Guildford Press.

Lloyd, L. (2000). Caring about carers: Only half the picture? *Critical Social Policy*, *20*(1), 136-150. doi: 10.1177/026101830002000106

Lof̈qvist, C., Granbom, M., Himmelsbach, I., Iwarsson, S., Oswald, F., & Haak, M. (2013). Voices on relocation and aging in place in very old age—A complex and ambivalent matter. *The Gerontologist*, *53*(6), 919-927. doi: 10.1093/geront/gnt034

Lyons, K. S., Zarit, S. H., Sayer, A. G., & Whitlatch, C. J. (2002). Caregiving as a dyadic process: Perspectives from caregiver and receiver. *The Journals of Gerontology: Series B*, *57*(3), P195-P204. doi: 10.1093/geronb/57.3.P195

Manley, K., & McCormack, B. (2008). Person-centred care. *Nursing management*, *15*(8), 12-13. doi: 10.7748/nm2008.12.15.8.12.c6874

McGraw, L. A., & Walker, A. J. (2004). Negotiating care: Ties between aging mothers and their caregiving daughters. *The Journals of Gerontology, series B*, *59*(6), S324-S332. doi: 10.1093/geronb/59.6.S324

Means, R., Richards, S., & Smith, R. (2008). *Community care. Policy and practice.* New York: Palgrave Macmillan.

Mello, J. d. A., Macq, J., Van Durme, T., Cès, S., Spruytte, C., Van Audenhove, et al. (2017). The determinants of informal caregivers' burden in the care of frail older persons: A dynamic and role-related perspective. *Aging & Mental Health*, *21*(8), 838-843. doi: 10.1080/13607863.2016.1168360

Mentzakis, E., McNamee, P., & Ryan, M. (2008). Who cares and how much: Exploring the determinants of co-residential informal care. *Review of Economics of the Household*, *7*(3), 283-303. doi: 10.1007/s11150-008-9047-0

Minkman, M. N. M. (2012). The current state of integrated care: An overview. *Journal of Integrated Care*, *20*(6), 346-358. doi: 10.1108/14769011211285147

Moos, R. H. (1979). Social ecological perspectives on health. In G. C. Stone, F. Coeh & N. E. Adler (Eds.), *Health psychology: A handbook* (pp. 523–547). San Francisco, CA: Jossey-Bass.

Nicholson, C., Meyer, J., Flatley, M., & Holman, C. (2013). The experience of living at home with frailty in old age: A psychosocial qualitative study. *International Journal of Nursing Studies*, *50*(9), 1172-1179. doi: 10.1016/j.ijnurstu.2012.01.006

OECD Health Statistics. (2018). *Health expenditure and financing*. Retrieved on 27 September 2018, from https://stats.oecd.org/index.aspx?DataSetCode=HEALTH_STAT

Oldenkamp, M., Hagedoorn, M., Slaets, J., Stolk, R., Wittek, R., & Smidt, N. (2016). Subjective burden among spousal and adult-child informal caregivers of older adults: Results from a longitudinal cohort study. *BMC Geriatrics*, *16*, 208. doi: 10.1186/s12877-016-0387-y

Ong, H. L., Vaingankar, J. A., Abdin, E., Sambasivam, R., Fauziana, R., Tan, M.-E., et al. (2018). Resilience and burden in caregivers of older adults: moderating and mediating effects of perceived social support. *BMC Psychiatry*, *18*, 27. doi: 10.1186/s12888-018-1616-z

Paraponaris, A., Davin, B., & Verger, P. (2012). Formal and informal care for disabled elderly living in the community: An appraisal of French care composition and costs. *The European Journal of Health Economics*, *13*(3), 327-336. doi: 10.1007/s10198-011-0305-3

Parks, J. A. (2003). *No place like home? Feminist ethics and home health care.* Bloomington, IN: Indiana University Press.

Penning, M. J. (1990). Receipt of assistance by the elderly: Hierarchical selection and task specificity. *The Gerontologist*, *30*(2), 220-227. doi: 10.1093/geront/30.2.220

Penninx, K., & Sprinkhuizen, A. (2011). *Krachtgerichte sociale zorg. Sociaal werk in de participatiesamenleving, een verkenning*. Utrecht: MOVISIE.

Peters, L. L., Boter, H., Buskens, E., & Slaets, J. P. J. (2012). Measurement properties of the Groningen Frailty Indicator in home-dwelling and institutionalised elderly people. *Journal of the American Medical Directors Association*, *13*(6), 546-551. doi: 10.1016/j.jamda.2012.04.007

Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*, *26*(1), 1-14. doi: 10.1037/a0021863

Puts, M. T. E., Lips, P., & Deeg, D. J. H. (2005). Static and dynamic measures of frailty predicted decline in performance-based and self-reported physical functioning. *Journal of Clinical Epidemiology*, *58*(11), 1188-1198. doi: 10.1016/j.jclinepi.2005.03.008

Puts, M. T. E., Shekary, N., Widdershoven, G., Heldens, J., Lips, P., & Deeg, D. J. H. (2007). What does quality of life mean to older frail and non-frail community-dwelling adults in the Netherlands? *Quality of Life Research*, *16*(2), 263-277. doi: 10.1007/s11136-006-

Raak, A., Mur-Veeman, I., Hardy, B., Steenbergen, M., & Paulus, A. (2003). *Integrated care in Europe: Description and comparison of integrated care in six EU countries.* Maarssen: Elsevier Gezondheidszorg.

Riedel, M. (2012). Financial support for informal care provision in European countries: a short overview. *Health and Ageing Newsletter*, *27*, 1-4.

Rodrigues, R., Schulmann, K., Schmidt, A., Kalavrezou, N., & Matsaganis, M. (2013). *The indirect costs of long-term care*. Retrieved on 27 September 2018, from https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=2ahUKEwjp8aXt8trdAhVFZVAKHWltA3cQFjAAegQICRAC&url=http%3A%2F%2Fec.europa.eu%2Fsocial%2FBlobServlet%3FdocId%3D11780%26langId%3Den&usg=AOvVaw3ivKop7rp7OjFaaIPnVMzi

Rockwood, K., Fox, R., Stolee, P., Robertson, D., & Beattie, B. (1994). Frailty in elderly people: An evolving concept. *Canadian Medical Association Journal*, *150*(4), 489-495.

Rolfson, D. B., Majumdar, S. R., Tsuyuki, R. T., Tahir, A., & Rockwood, K. (2006). Validity and reliability of the Edmonton Frail Scale. *Age and Ageing*, *35*(5), 526–529. doi: 10.1093/ageing/afl041

Romero-Ortuno, R., Walsh, C. D., Lawlor, B. A., & Kenny, R. A. (2010). A Frailty Instrument for primary care: findings from the Survey of Health, Ageing and Retirement in Europe (SHARE). *BMC Geriatrics*, *10*, 57. doi: 10.1186/1471-2318-10-57

Ryan, L. H., Smith, J., Antonucci, T. C., & Jackson, J. S. (2012). Cohort differences in the availability of informal caregivers: Are the boomers at risk? *The Gerontologist*, *52*(2), 177-188. doi: 10.1093/geront/gnr142

Sevenhuisen, S. (1998). *Citizenship and the ethics of care: Feminist considerations on justice, morality and politics*. London: Routledge.

Shanas, E. (1979). Social myth as hypothesis: The case of the family relations of old people. *The Gerontologist*, *19*(1), 3-9. doi: 10.1093/geront/19.1.3

Sims-Gould, J., & Martin-Matthews, A. (2010). We share the care: Family caregivers' experiences of their older relative receiving home support services. *Health and Social Care in the Community*, *18*(4), 415-423. doi: 10.1111/j.1365-2524.2010.00913.x

Sipsma, D. H. (1986). *Sociale geriatrie in theorie en praktijk*. Almere: Promeda.

Smetcoren, A.-S. (2015). *'I'm not leaving!?' Critical perspectives on 'ageing in place'* (Doctoral dissertation). Brussel: Vrije Universiteit Brussel.

Stabile, M., Laporte, A., & Coyte, P. C. (2006). Household responses to public home care programs. *Journal of Health Economics*, *25*(4), 674-701. doi: 10.1016/j. jhealeco.2005.03.009

Stones, D., & Gullifer, J. (2016). 'At home it's just so much easier to be yourself': Older adults' perceptions of ageing in place. *Ageing & Society*, *36*(3), 449-481. doi: 10.1017/So144686X14001214

Stuckler, D., Reeves, A., Loopstra, R., Karanikolos, M., & McKee, M. (2017). Austerity and health: the impact in the UK and Europe. *European Journal of Public Health*, *27*(5), 18-21. doi: 10.1093/eurpub/ckx167

Suanet, B., Broese van Groenou, M., & Van Tilburg, T. (2012). Informal and formal home-care use among older adults in Europe: Can cross-national differences be explained by societal context and composition? *Ageing & Society*, *32*(3), 491–515. doi: 10.1017/S0144686X11000390

Suanet, B., van Tilburg, T. G., & Broese van Groenou, M. I. (2013). Nonkin in older adults' personal networks: More important among later cohorts? *The Journals of Gerontology: Series B*, *68*(4), 633-643. doi: 10.1093/geronb/gbt043

Sullivan, P. W. (1992). Reclaiming the community: The strengths perspective and deinstitutionalization. *Social work*, *37*(3), 204-209. doi: 10.1093/sw/37.3.204

Sundström, G., Fransson, E., Malmberg, B., & Davey, A. (2009). Loneliness among older Europeans. *European Journal of Ageing*, *6*(4), 267-275. doi: 10.1007/s10433-009-0134-8

Tronto, J. C. (2001). An ethic of care. In M. B. Holstein & P. B. Mitzen (Eds.), *Ethics in community-based elder care* (pp. 60-68). New York: Springer Publishing Company, Inc.

Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care*. London: Routledge.

United Nations. (2015). *World population ageing 2015*. Retrieved on 27 September 2018, from http://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2015_Report.pdf

Vancea, M., & Solé-Sasals, J. (2016). Population aging in the European Information Societies: Towards a comprehensive research agenda in eHealth innovations for elderly. *Aging and Disease*, *7*(4), 526-539. doi: 10.14336/AD.2015.1214

van der Vorst, A., Zijlstra, G. A. R., De Witte, N., Vogel, R. G. M., Schols, J. M. G. A., Kempen, G. I. J. M., et al. (2017). Explaining discrepancies in self-reported quality of life in frail older people: A mixed-methods study. *BMC Geriatrics*, *17*, 251. doi: 10.1186/s12877-017-0641-y

van Dijk, H. M., Cramm, J. M., & Nieboer, A. (2013). The experiences of neighbour, volunteer and professional support-givers in supporting community dwelling older people. *Health and Social Care in the Community*, *21*(2), 150-158. doi: 10.1111/hsc.12006

Vandeurzen, J. (2016). *Nabije zorg in een warm Vlaanderen. Vlaams Mantelzorgplan 2016–2020*. Retrieved on 27 September 2018, from https://www.vlaanderen.be/nl/publicaties/detail/nabij-zorg-in-een-warm-vlaanderen-vlaams-mantelzorgplan-2016-2020

Van Houtven, C. H., & Norton, E. C. (2004). Informal care and health care use of older adults. *Journal of Health Economics*, *23*(6), 1159–1180. doi: 10.1016/j. jhealeco.2004.04.008

van Kempen, J. A. L., Robben, S. H. M., Zuidema, S. U., Olde Rikkert, M. G. M., Melis, R. J. F., & Schers, H. J. (2012). Home visits for frail older people: a qualitative study on the needs and preferences of frail older people and their informal caregivers. *British Journal of General Practice*, *62*(601), 554–560. doi: 10.3399/bjgp12X653606

Verbakel, E., Tamlagsrønning, S., Winstone, L., Fjær, E. L., & Eikemo, T. A. (2017). Informal care in Europe: Findings from the European Social Survey (2014) special module on the social determinants of health. *European Journal of Public Health*, *27*(1), 90–95. doi: 10.1093/eurpub/ckw229

Vermeiren, S., Vella-Azzopardi, R., Beckwée, D., Habbig, A.-K., Scafoglieri, A., Jansen, B., et al. (2016). Frailty and the prediction of negative health outcomes: A meta-analysis. *Journal of the American Medical Directors Association*, *17*(12), 1163.e1-1163.e17. doi: 10.1016/j.jamda.2016.09.010

Verver, D., Merten, H., Robben, P., & Wagner, C. (2018). Care and support for older adults in the Netherlands living independently. *Health and Social Care in the Community*, *26*(3), e404-e414. doi: 10.1111/hsc.12539

Waerness, K. (1990). Informal and formal care in old age: What is wrong with the new ideology in Scandinavia today? In C. Ungerson (Ed.), *Gender and caring: Work and welfare in Britain and Scandinavia* (pp. 110-132). London: Harvester Wheatsheaf.

Ward-Griffin, C. (2001). Negotiating care for frail elders: Relationships between Community nurses and family caregivers. *Canadian Journal of Nursing Research*, 33(2), 63-81.

Ward-Griffin, C., & Marshall, V. (2003). Reconceptualizing the relationship between ''public'' and ''private'' eldercare. *Journal of Aging Studies*, *17*(2), 189-208. doi: 10.1016/S0890-4065(03)00004-5

Warmoth, K., Lang, I. A., Phoenix, C., Abraham, C., Andrew, M. K., Hubbard, R. E., et al. (2016). 'Thinking you're old and frail': A qualitative study of frailty in older adults. *Ageing & Society*, *36*(7), 1483-1500. doi: 10.1017/S0144686X1500046X

Wiles, J. (2005). Conceptualising place in the care of older people: the contributions of geographical gerontology. *Journal of Clinical Nursing*, *14*(s2), 100-108. doi: 10.1111/j.1365-2702.2005.01281.x

Wiles, J. L., Leibing, A., Guberman, N., Reeve, J., & Allen, R. E. S. (2012). The meaning of 'ageing in place' to older people. *The Gerontologist*, *52*(3), 357-366. doi: 10.1093/geront/gnr098

Wolff, J. L., Mulcahy, J., Huang, J., Roth, D. L., Covinsky, K., & Kasper, J. D. (2017). Family caregivers of older adults, 1999-2015: Trends in characteristics, circumstances, and role-related appraisal. *The Gerontologist*. doi:10.1093/geront/gnx093

World Bank Group. (2018). *Age dependency ratio, old (% of working-age population)*. Retrieved on 27 September 2018, from https://data.worldbank.org/indicator/SP.POP.DPND.OL

World Health Organization. (2004). *A glossary of terms for community health care and services for older persons*. Retrieved on 27 September 2018, from http://www.who.int/kobe_centre/ageing/ahp_vol5_glossary.pdf

World Health Organization. (2009). *Addressing financial sustainability in health systems*. Retrieved on 27 September 2018, from http://www.euro.who.int/__data/assets/pdf_file/0005/64949/E93058.pdf

World Health Organization. (2015). *World report on ageing and health*. Retrieved on 27 September 2018, from http://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf;jsessionid=565A0108A1F4B5AA3D5E2FD81B1D4755?sequence=1

Yokota, R. T. d. C., Van der Heyden, J., Nusselder, W. J., Robine, J.-M., Tafforeau, J., Deboosere, P., et al. (2016). Impact of chronic conditions and multimorbidity on the disability burden in the older population in Belgium. *The Journals of Gerontology: Series A*, *71*(7), 903-909. doi: 10.1093/gerona/glv234

Zaslavsky, O., Woods, N. F., LaCroix, A. Z., Cauley, J. A., Johnson, K. C., Cochrane, B. B., et al. (2016). Identification of risk factors for mortality and poor-quality-of-life survival in frail older women participating in the Women's Health Initiative observational study. *Journal of the American Geriatrics Society*, *64*(4), 831-837. doi: 10.1111/jgs.14042

Part 2

Data and methodology

Chapter 3. Description of data used for the dissertation

1. Using a mixed methods research paradigm

This dissertation is characterised by a mixed methods approach and uses both quantitative and qualitative research methods to explore care networks of frail, older adults (Christensen, Johnson, & Turner, 2011). According to Silva, Warde and Wright (2009) mixed method approaches are needed to investigate complex social phenomena. Mixed methods research "*recognises the importance of traditional quantitative and qualitative research but also offers a powerful third paradigm choice that often will provide the most informative, complete, balanced, and useful research results*" (Johnson, Onwuegbuzie, & Turner, 2007, p. 129). Mixed methods research is an approach that moves past the paradigm wars by offering a logical and practical alternative, and is inclusive, pluralistic and complementary (Johnson & Onwuegbuzie, 2004). Philosophically, mixed methods research makes use of the pragmatic method (Christensen et al., 2011; Johnson et al., 2007). Researchers adhere to a compatibility thesis, which concerns the idea that quantitative and qualitative methods are complementary and can be used effectively together in a single research study (Christensen et al., 2011).

In the social science methodological literature, Campbell and Fiske (1959) formalised the practice of using multiple research methods and introduced the concept of triangulation, which refers to the use of multiple methods as part of the validation process of research results. Denzin (1978) distinguished within-methods triangulation, which refers to the use of either multiple quantitative or multiple qualitative approaches, from between-methods triangulation, which involves the use of both quantitative and qualitative approaches. Denzin (1978) recommended the use of between-method triangulation and indicated that by using mixed methods, the bias inherent in particular data sources, investigators and methods will be cancelled out when used in combination with other data sources, investigators, and methods. The present dissertation is characterised by a simultaneous triangulation (Morse, 1991) due to its simultaneous use of qualitative and quantitative methods in which there is limited interaction between the data sources, but the findings complement one another at the data interpretation stage.

Within the dissertation, we made use of both qualitative and quantitative data. One study was conducted using quantitative data of the Belgian Ageing Studies research program (De Donder et al., 2014), two studies were conducted using qualitative data from the second phase of the D-SCOPE project (Dury et al., 2018) and one quantitative study was conducted using quantitative data from the D-SCOPE frailty program (Lambotte et al., 2018). Although all projects are described within the relevant chapters of this dissertation, a brief description is given below for the Belgian Ageing Studies research program and the (second phase of the) D-SCOPE project. The published protocol of the third phase of the D-SCOPE project, the D-SCOPE frailty program, is provided as separate chapter (chapter 4).

2. The Belgian Ageing Studies

The Belgian Ageing Studies (BAS) is a research program (2002 – ongoing), which monitors the challenges and opportunities, and issues of quality of life among community-dwelling older adults (60+) in order to provide tools for evidence-based 'age-friendly' policies at the local level (see De Donder et al., 2014 for a detailed description of the research program). The BAS has 4 objectives:

- Providing an instrument to measure the living conditions and quality of life of community-dwelling older adults in municipalities;
- Promoting evidence-based local policy by providing input and mobilising knowledge for planning and inclusive policy programmes;
- Supporting the process of creating age-friendly communities;
- Exploring trends in particular municipalities by conducting follow-up BAS studies.

In order to achieve these objectives, the BAS (1) developed a standardised methodology in co-creation with older adults, senior organisations, senior advisory boards, local authorities, the Vrije Universiteit Brussel, University College Ghent and other stakeholders, and (2) adopted a participatory action research process (Jason, Keys, Suarez-Balcazar, Taylor, & Davis, 2004; Reason & Bradbury, 2008; Stringer, 2007). An important criterion of the BAS is the central role of participants (Balcazar et al., 2004), as the participatory methodology within the Belgian Ageing Studies is peer research. Older adults are not only the research target group but also co-developers and actors within the research program. Older adults are full participants in the research process and participate in the different phases and reflection: in carrying out the research, evaluating the program and in developing evidence-based policy and action plans.

The BAS gather data on community-dwelling individuals aged 60 years and over about their perceptions on housing conditions, informal and formal care, frailty, feelings of unsafety, civic engagement, social networks, retirement, etc. Addresses are randomly selected from the census records in each municipality and in order to ensure the representation of vulnerable age groups, a proportionally stratified sample is drawn using particular quota for gender and age (60-69 years, 70-79 years and 80+ years). Each sample reflects the underlying population of the municipality. The age cut-off of 60 years relates to the Flemish policy background in which the BAS was developed, namely the introduction of the Flemish Decree on 'Stimulation of an inclusive Flemish policy on older adults and their political participation'. The decree indicates that municipalities have to create a local senior policy plan for their older citizens and determines an older individual from the age of 60 (Flemish Government, 2004).

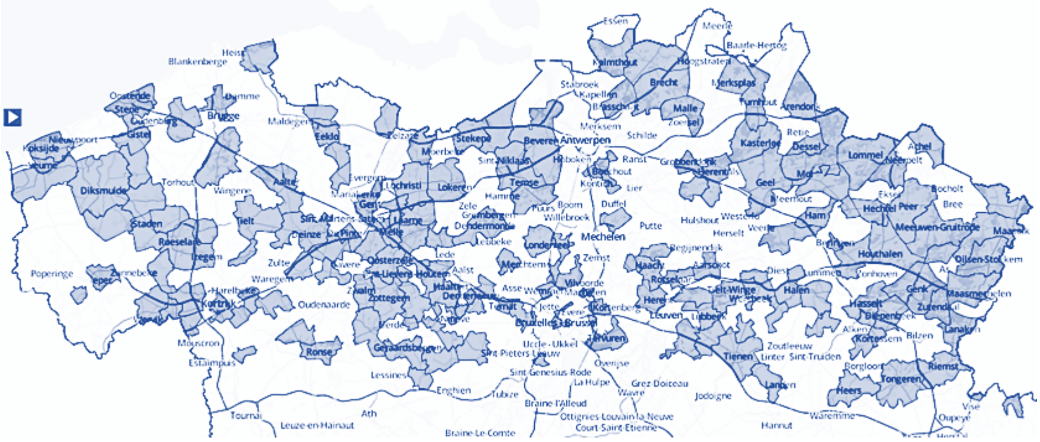


Figure 5. Participating municipalities in the Flemish region of Belgium (2004 – 2017)

For this dissertation, we used data (N = 38,066) collected between 2008 - 2014 in 83 municipalities to investigate the relation between the different combinations of informal and formal care use (i.e. receiving care from nuclear family, extended family, friends and acquaintances, neighbours, general practitioner, home nurse and formal home assistance) and multidimensional frailty (i.e. physical, psychological, social and environmental frailty).

3. The D-SCOPE research project

The Detection, Support and Care for Older people: Prevention and Empowerment (D-SCOPE) project (2015-2018) aims to identify strategies for proactive detection of community-dwelling older adults at risk for frailty, in order to guide them towards appropriate care and support, with a focus on empowerment. The D-SCOPE project is an international multidisciplinary research project, assembling researchers from several disciplines (e.g. educational sciences, psychology, medical sciences, gerontology, etc.) from the Vrije Universiteit Brussel, Katholieke Universiteit Leuven, Universiteit Antwerpen, Universiteit Maastricht and Hogeschool Gent. The D-SCOPE project is commissioned by the Agency for Innovation by Science and Technology and is embedded in the Strategic Basic Research [IWT-140027-SBO].

D-SCOPE
detection, support and care for older people:
prevention and empowerment

Figure 6 provides a schematic overview of the D-SCOPE model. The D-SCOPE project contributes to the development of a new approach towards the prevention of frailty in older adults in order to age well in place, and comprises three research phases: (1) the development of multidimensional frailty risk profiles (Dury et al., 2017); (2) the identification of balancing factors and positive outcomes (Dury et al., 2018); and (3) the development of a frailty-balance instrument and intervention (Lambotte et al., 2018). Therefore, a multidimensional approach for frailty is applied by the use of the Comprehensive Frailty Assessment Instrument (CFAI) (De Witte et al., 2013) and the Comprehensive Frailty Assessment Instrument Plus (CFAI-Plus) (De Roeck et al., 2018). The D-SCOPE model is dynamic as life events and interventions can influence frailty, frailty-balance and positive outcomes.

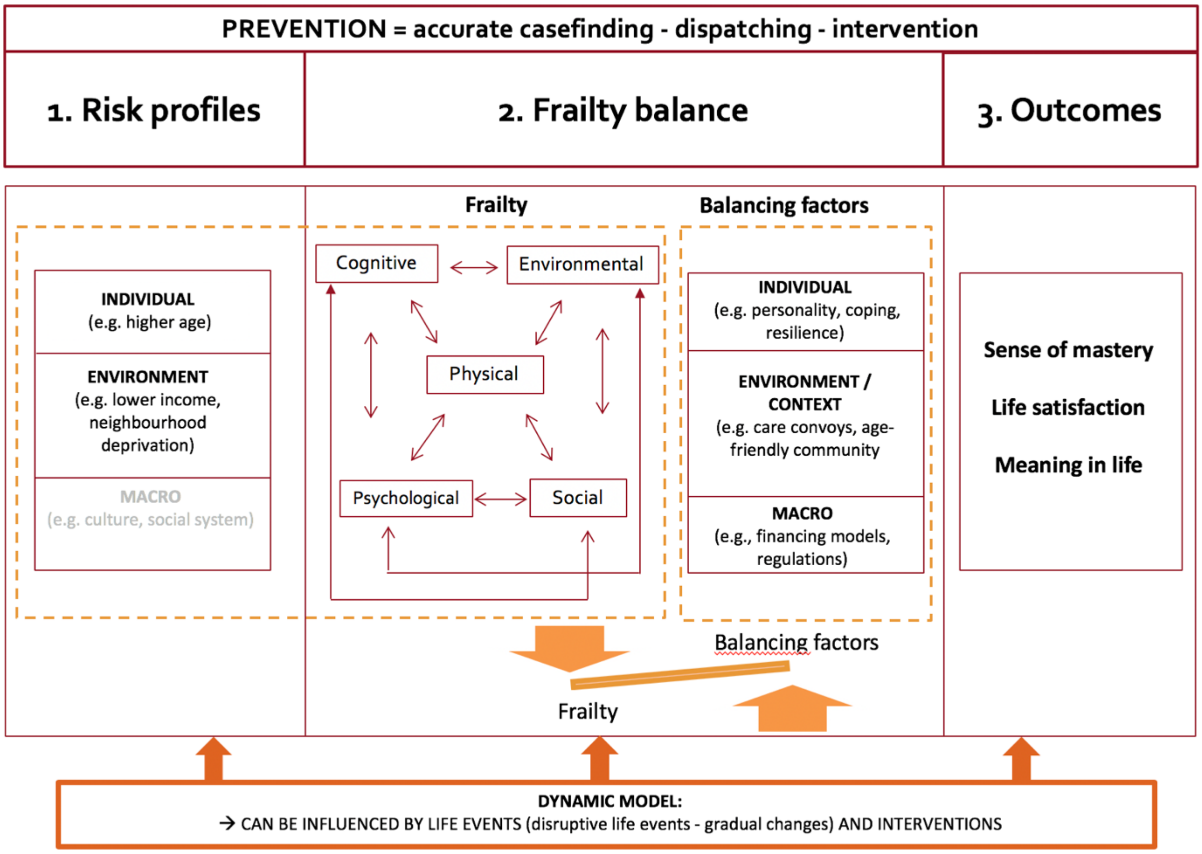


Figure 6. The D-SCOPE model

Chapter 4. Randomized controlled trial to evaluate a prevention program for frail community- dwelling older adults: a D-SCOPE protocol

Manuscript published

Lambotte, D., De Donder, L., De Roeck, E. E., Hoeyberghs, L. J., van der Vorst, A., Duppen, D., Van der Elst, M., Fret, B., Dury, S., Smetcoren, A.-S., Kardol, M. J. M., Engelborghs, S., De Deyn, P. P., De Witte, N., Schols, J. M. G. A., Kempen, G. I. J. M., Zijlstra, G. A. R., De Lepeleire, J., Schoenmakers, B., Verté, D., & Dierckx, E. (2018). Randomized controlled trial to evaluate a prevention program for frail community-dwelling older adults: a D-SCOPE protocol. *BMC Geriatrics*, *18*, 194. doi: 10.1186/s12877-018-0875-3

Abstract

Background: Frail, community-dwelling older adults, whom might experience problems regarding physical, cognitive, psychological, social and environmental factors, are at risk for adverse outcomes such as disability, institutionalization and mortality. People in need of help do not always find their way to care and support services and are left undetected. The aim of the D-SCOPE project is to detect frail, community-dwelling older adults who previously went unnoticed and to improve their access to care and support. Goal is to increase their frailty-balance, quality of life, meaning in life, life satisfaction, mastery, community inclusion and ageing well in place.

Methods/design: The study is a prospective, longitudinal randomized four-armed controlled trial with follow-up at 6 months. The study group aims to include 900 community-dwelling older adults aged 60 years and over from 3 municipalities in Flanders (Belgium). While selecting the study group, risk profiles for frailty will be taken into account. Participants will be randomly selected from the census records in each municipality. Data will be collected prospectively at baseline (T0) and at follow-up, 6 months after baseline (T1). At baseline, participants who are at least mild frail on one of the 5 domains of frailty (CFAI-plus) or feel frail based on the subjective assessment of frailty will be randomly assigned to (1) the study group or (2) the control group. A mixed method design with the inclusion of quantitative and qualitative data analyses will be used to evaluate the efficacy and experiences of the detection and prevention program on frailty.

Discussion: The study will contribute to an innovative vision concerning the organization of care and support, and a timely and accurate detection and support of community-dwelling older adults at risk for frailty.

Trial registration: This trial was registered at ClinicalTrials.gov, on May 26, 2017, identifier: NCT03168204.

Keywords

Randomized controlled trial; frailty; community-dwelling; prevention; detection; care and support

1. Background

Frailty is a common phenomenon in community-dwelling older adults. Research indicates that the average prevalence for multidimensional frailty is 13.6% and 33.5% for prefrailty in community-dwelling older adults (Collard, Boter, Schoevers, & Oude Voshaar, 2012). Frailty increases with age (Collard et al., 2012; Lee, Kawas, Gibbs, & Corrada, 2016). For example, a systematic review on the prevalence of frailty indicates that the prevalence for oldest-old people is 15.7% (80–84 years) and 26.1% (≥ 85 years) (Collard et al., 2012). Within an aging society, more and more per- sons are confronted with frailty and the demand for care and support increases (Bolin, Lindgren, & Lundborg, 2008; Colombo, Llena-Nozal, Mercier, & Tjadens, 2011; Jacobs, Van Tilburg, Groenewegen, & Broese van Groenou, 2016; Yang, Norton, & Stearns, 2003). Although frailty has mainly been approached as a physical issue (Fried et al., 2001; Viana et al., 2013), different researchers point to the necessity to operationalize frailty as a multidimensional and dynamic concept that considers the complex interplay of physical, cognitive, psychological, social and environmental factors (Armstrong, Stolee, Hirdes, & Poss, 2010; Bergman et al., 2007; De Witte et al., 2013a, b). Not only researchers identify frailty in a multidimensional way, older adults themselves experience frailty as more than merely a physical issue as well (Grenier, 2007).

As older adults become frail, different dimensions of their lives such as their quality of life and feelings of control (e.g., mastery) may be affected (Gobbens & van Assen, 2014; Kojima, Iliffe, Jivraj, & Walters, 2016; Lee, Chen, Peng, Chiou, & Chou, 2016), and their risk for adverse outcomes such as hospitalization and institutionalization increases (Ament, de Vugt, Verhey, & Kempen, 2014; Espinoza & Walston, 2005; Rockwood et al., 2004). A study by Rockwood et al. (2004) indicates that frailty is one of the most important predictors of death and institutionalization. Governments are implementing a proactive care approach in order to prevent or delay (the high costs of) such institutionalization and other adverse outcomes, and stimulate older adults to stay in their own environment as long as possible with good quality of life (Scharlach, 2012). This so-called policy on aging in place is in line with the wish of the majority of older adults (Löfqvist et al., 2013), even when they need care and support, have economic difficulties or live in inadequate housing or deprived environments (Smetcoren et al., 2017a).

People in need of care and support do not always find the appropriate services and are often left undetected (Willemé, 2010). Nowadays in several European countries, also in Belgium, there is insufficient continuity and coherence between the different care and support services in the community (Paulus, Van den Heede, & Mertens, 2012). Research indicates that 6.4% of Flemish older adults in need of care and support do not receive any care at all (De Witte, Buffel, De Donder, Dury, & Verté, 2010). As a result, the problems and needs of older adults are frequently not recognized or treated in time, leading to a decline of their autonomy and quality of life. Furthermore, current initiatives to proactively identify health and social problems in (frail) older adults insufficiently address needs of (frail) older people (Lette, Baan, van den Berg, & de Bruin, 2015). This suggests a need for rethinking the organization of the support and care system (Nyweide, Anthony, Chang, & Goodman, 2011). For instance, empowering older adults to manage their own health and social issues and improving their access to community care and support needs to be ameliorated (Tindale et al., 2011). Therefore, early detection of frailty and tailored care and support are of main importance (Dury et al., 2017).

Within the detection and support of frail, older adults, a critical consideration should be made. Frailty in older adults does not necessarily have negative consequences in daily life, especially when the right care and support is present. This suggest that besides measuring the deficits of frailty, there is also a need to take into account the strengths and resources of older adults (Buntinx, Paquay, Fontaine, Ylieff, & De Lepeleire, 2004). Therefore, we prefer to use balancing factors and the frailty balance as terminology. The latter is in line with Baltes and Smith (2003) who suggest the recognition of two faces of human aging, including both the gains and the losses. Such gains might also be seen in the context of losses, as older adults may unfold unexpected substitute skills, collaborative relationships or creative strategies to overcome limitations (Hansson, Robson, & Limas, 2001). For instance, two individuals with a similar frailty level or profile can have different needs of support because their 'frailty-balance' is different (de Blok, Meijboom, Luijkx, & Schols, 2009). Thereby, they might differ in terms of autonomy, resilience, social contacts and received informal and formal care. Interventions are necessary to close of diminish the distance of the gap between gains and losses, and to restore the frailty balance (de Blok et al., 2009). Furthermore, older adults need to be supported in using and further develop their own competences (Buntinx et al., 2004).

Findings from aforementioned studies, additional literature reviews (De Roeck, Engelborghs, & Dierckx, 2016a; Duppen et al., 2017; van der Vorst et al., 2016) and preliminary studies (De Roeck et al., 2016b; Dury et al., 2017, 2018; Fret et al., 2017; Smetcoren et al., 2018; Smetcoren, Dury, De Donder, & Dierckx, 2017b; van der Vorst et al., 2017) led to the design of a multidimensional detection and prevention program for frail, community-dwelling older adults (D-SCOPE) aimed to improve access to care and support. Research indicates that for both men and women, increased age, having no partner, having moved in the previous 10 years, having a lower educational level and having a lower household income are risk characteristics for frailty (Dury et al., 2017). Furthermore, different risk profiles for frailty in older adults exist according to gender and the type of frailty (physical, psychological, social, environmental and total frailty). In addition to frailty, it is also important to identify and strengthen the competences and resources of older adults (Buntinx et al., 2004; van der Vorst et al., 2017). For example, a literature review concerning the social environment of older adults indicates that different aspects of the social environment such as subjective neighborhood characteristics are protective for frailty in community-dwelling older adults (Duppen et al., 2017). Another systematic review found a high level of physical activity and being married to be protective against developing limitations in ADLs in community-dwelling persons aged 75 years and over (van der Vorst et al., 2016).

This article describes the design of the Randomized Controlled Trial (RCT) aimed to evaluate a detection and prevention program on frailty (D-SCOPE), which will create a continuum of care and support for frail, community-dwelling older adults, from early detection, over intervention, to follow-up. The D-SCOPE frailty program intends to develop methods to easily, accurately and timely detect and prevent a negative frailty-balance in older adults. The intervention will include tailored care and support and long-term care follow-up. The RCT will explore if the D-SCOPE frailty program improves the quality and efficacy of care and support given to frail, community-dwelling older adults, which ultimately would increase their quality of life, meaning in life, life satisfaction, mastery, community inclusion and ageing well in place.

The objectives of this trial are to conduct:

1. An effect evaluation to determine if the D-SCOPE frailty program
    a. detects frail, community-dwelling older adults who otherwise would have remained undetected (i.e., older adults who are at least mild frail on one of the 5 domains of frailty of the CFAI-plus or feel frail based on the subjective

    assessment of frailty, who do not receive the necessary care and support, by using risk profiles based on age, gender, marital status, migration background and being moved in the past 10 years (Dury et al., 2017)
   b. guides frail, community-dwelling older adults to- wards appropriate care and support (by recognizing, valorizing and strengthening their competences, strengths and resources)
   c. prevents that care and support is discontinued (by the older person itself, the care and support organization, discontinuity or care selection by the organization) and thus reduce dropout
   d. improves the frailty-balance of community- dwelling older adults (i.e., effect on frailty, balancing factors and outcomes)
2. A process evaluation to determine the obstructing and facilitating components when implementing the D-SCOPE frailty program:
   a. On the micro-level: concerning the individual capacities of key-actors (volunteers, municipal health and social care professionals, etc.) such as motivation, needed outcomes, required training and features of older adults (financial vulnerability, care expenditures, etc.)
   b. On the meso-exo-level: concerning interpersonal relations, management, administrative support, professional networks, etc.
   c. On the macro-level: concerning the broader care system, present care and support organizations in the network, political recommendations, available resources, etc.

2. Methods/design

2.1. Study design

The D-SCOPE frailty program concerns a Randomized Controlled Trial (RCT). The RCT will compare usual care with an intervention that include tailored care and support and long-term care follow-up. Figure 1 presents an overview of the study design. The D-SCOPE frailty program will start with targeted case-finding, which refers to the selections from the census records based on eligibility criteria (Dury et al., 2017).

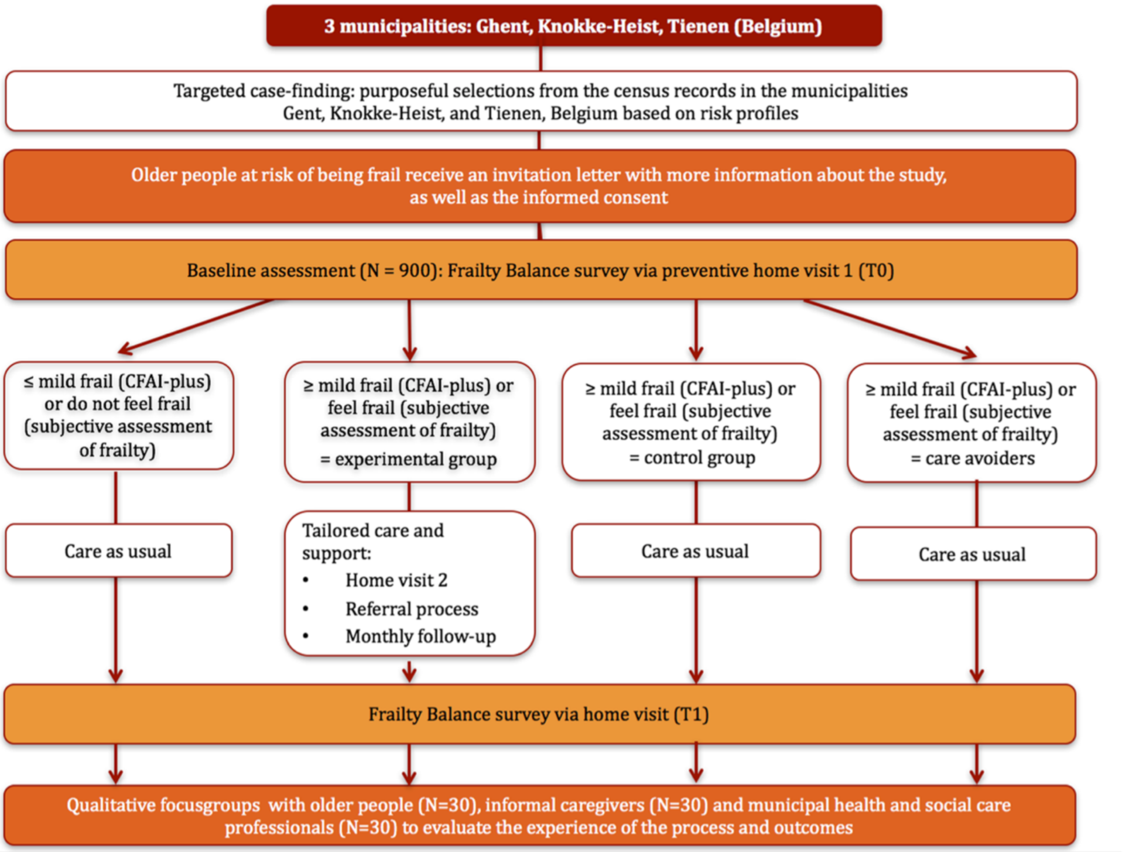


Figure 7. Flow diagram of the D-SCOPE frailty program

Older adults will receive an invitation letter explaining the purpose of the study, the way on which the study will be conducted and the expectations towards people who agree to participate. A trained volunteer or a researcher will contact them in person and will inform them face to face about the study. Participants will also receive the informed consent form and a letter for the general practitioner explaining the D-SCOPE frailty program. Respondents will have the opportunity to ask questions if anything would remain unclear. Older adults willing to participate will undergo the baseline assessment (T0) after signing the informed consent.

Older adults who are at least mild frail on one of the 5 domains of frailty (CFAI-plus) or feel frail based on the subjective assessment of frailty will be randomly assigned to either (1) the experimental group or (2) the control group. Older adults with no-to-low frailty (CFAI-plus) or who do not feel frail (subjective assessment of frailty) will be grouped into a third group. A fourth group will include frail, older adults willing to participate in the T0 and T1 assessment but not in the intervention part. All groups except for the experimental group will receive care as usual.

All older participants will be assessed after a 6 months' period. The study will include an effect evaluation and a process evaluation of the RCT. The effect study will be conducted using a quantitative evaluation of the out- come measures for frail, community-dwelling older adults. The process evaluation will be performed by a quantitative monitoring of the experimental group (including follow-up telephone interviews) and qualitative focus groups with older adults, informal caregivers and municipal health and social care professionals in each municipality.

The baseline assessment T0 will begin in June 2017 until October 2017. The study assessment T1 will begin in December 2017 until April 2018. The intervention will take place between June 2017 and March 2018, be- tween the baseline assessment T0 and the study assessment T1. The qualitative evaluation will take place in March and April 2018. The data analysis will take place between April 2018 and June 2018.

The content of the program has been developed in close collaboration with representatives of different home care and support levels, i.e. general practitioners, home care organizations, social service of the municipalities, home nurses, older people's organizations, centers of expertise in housing and care, care insurances companies, universities, etc.

2.2. Setting

The RCT will be conducted in three municipalities in Flanders (Belgium): Knokke-Heist, Ghent and Tienen (N = 900, 300 in each municipality). Each municipality was chosen due to their specific characteristics (Table 3). First, the municipalities differ in terms of socio-economic environment (Belfius, 2017). Knokke-Heist is defined as a coastal town, Ghent as a big city and Tienen as a medium-sized town. Second, demographically and regarding welfare and health, Knokke-Heist has been confronted with a sharp in- crease of older adults despite a low number of places in residential care and a low number of informal care and home care. Like Knokke-Heist, Tienen has more older adults (both 65+ and 80+) than the percentage of the Flemish region. Finally, the population in Ghent has a lower average income in comparison with the Flemish average.

Table 3. Characteristics of the 3 localities (Moons, 2016a,b,c)

	Knokke-Heist (Moons, 2016a)	Ghent (Moons, 2016b)	Tienen (Moons, 2016c)	Flemish region (Moons, 2016a,b,c)
Demographic data (2016)				
Total number of inhabitants	33,311	257,029	34,185	6,477,804
Population growth since 2005	98.5	111.3	107.7	107.2
Total number of older inhabitants	11,310	42,706	7,243	1,265,666
Older population growth since 2005	128.5	102.1	111.2	117.9
% older adults (65 years and over)	34.0%	16.6%	21.2%	19.5%
% older adults (80 years and over)	9.9%	5.5%	6.5%	5.9%
Socio-economic data (2013)				
Average income per capita in €	23,374	17,477	18,479	18,163
Welfare and health data				
Number of places in residential care in 2016 per 1000 older adults (>65y)	58	84.6	90.2	76
Number of entitled informal and home care in 2015 per 1000 older adults (>65y)	56.3	69	132.1	98.2

2.3. Setting

This study protocol was reviewed and approved by the medical ethics committee of the Vrije Universiteit Brussel, Brussels, Belgium (reference number: B.U.N. 143,201,630,458). Prior to the baseline assessment and start of the intervention in the experimental group, written consent will be obtained from all participants.

2.4. Participants and eligibility criteria

Study participants will be community-dwelling older adults aged 60 years and over. In order to explore the most efficient selection strategy to detect frail, older adults, two randomized selections, with replacement addresses, from the census records will take place in each municipality. Each randomized selection in each municipality will include 150 participants. The two stratified samples will be based on previous research on risk profiles for frailty (Dury et al., 2017). Risk characteristics for frailty are gender, age, marital status, moved in the past 10 years and migration background. In the first sample (n = 450) older participants will need to fulfil at least one criterion. This implies that the participants will be women or aged 70 years and over or not have a partner or have moved in the past 10 years or will have a migration background. In the second sample (n = 450) all older participants will need to fulfil all selection criteria. This implies that older participants will be aged 70 years and over, have no partner, and moved last 10 years. The second sample will exclude the variable migration back- ground due to too small samples within the three selected municipalities.

Exclusion criteria will be current hospitalization, institutionalization, when the older participant himself or his/her informal caregiver indicates that the older participant is not able to participate or if the interviewer notes that the older participant is cognitively not capable to provide adequate answers.

Older adults will be included in the RCT if they are at least mild frail on one of the 5 domains of the CFAI-plus (i.e., ≥ 25 for physical frailty, ≥ 12.52 for cognitive frailty, ≥ 20 for psychological frailty, ≥ 37.5 for social frailty and ≥ 5 for environmental frailty) or feel frail based on the subjective assessment of frailty (i.e. at least agree with the statement), and accept to participate in the intervention.

2.5. Randomization

Eligible participants will be randomly assigned directly after the baseline assessment by the principal researcher, using computer-generated randomization to either the control or the experimental group.

2.6. Intervention

The intervention contains several steps in order to empower older adults and improving their access to care and support (Tindale et al., 2011). Older participants assigned to the experimental group after the first home visit containing the T0 baseline assessment will be contacted by a professional from the social service of the municipality for a second home visit. These professionals will already be experienced with conducting home visits and will receive training and instructions concerning multidimensional frailty, frailty-balance and taking into account the strengths and competences of older adults and their informal caregivers. During the second home visit, the professional from the social service of the municipality will further explore the older adult's competences, needs and preferences. Based on the results of the baseline assessment and on the results of the second home visit, the professional from the social service of the municipality will propose a type of intervention. The decision and organization of tailored care and support will be made together with the older participant and his/her environment. The older participant will be accompanied in the referral once decided in which organization/form of intervention the older participant will participate in order to reduce dropout. The older participant will receive tailored care and support whereby his competences, strengths and resources will be supported (Buntinx et al., 2004). The intervention will depend on the availability of the care and support services in the municipality, and could be formal (e.g., home care) or informal (e.g., activities of an older adult's association). A professional from the social service of the municipality will monitor which care the participant receives, when the older person cancels the care and support and if everything is going according to his/her wishes. This will be done monthly by telephone.

2.7. Measurements

Table 4 presents the outcomes of the effect and process evaluation.

Effect evaluation

Primary outcome measures

The primary outcomes of the effect evaluation will be quality of life, meaning in life, life satisfaction, mastery, community inclusion and ageing well in place.

Quality of life will be measured by the use of one item from the abbreviated version of the World Health Organization Quality of Life (WHOQOL-BREF, World Health Organization, 1996). *Meaning in life* will be evaluated with the Meaning in Life Questionnaire (MLQ) and will assess perceived meaning in life by the use of 5 items (Steger, Frazier, Oishi, & Kaler, 2006). *Life satisfaction* will be measured by using the Satisfaction with Life Scale, a validated scale which measures global life satisfaction (Diener, Emmons, Larsen, & Griffin, 1985). To assess *mastery*, a questionnaire which evaluates to what extent people feel they exert control over existing circumstances of their lives with 4 items will be used (Pearlin, Nguyen, Schieman, & Milkie, 2007). In addition, one self-constructed item will assess mastery in relation to others (Verkerk, 2001). *Community inclusion* will be measured by using 1 item from the Community

Integration Measure (CIM) and will ask the participants to what extent they feel like part of the community (McColl, Davies, Carlson, Johnston, & Minnes, 2001). *Ageing well in place* will be assessed using a self-constructed question and will explore to what extent the older participant feels he/she lives at home in a qualitative way. Older participants will also be asked to rate the outcomes quality of life, meaning in life, autonomy and community inclusion on a scale from 0 to 10.

Secondary outcome measures

Secondary outcomes will be multidimensional frailty, physical phenotype of frailty, feeling frail, balancing factors (i.e., resilience, coping, help needed for activities in daily life, informal and formal care, medical care, leisure time, neighborhood), future perspective and life-events.

The Comprehensive Frailty Assessment Instrument (CFAI-plus) will measure *multidimensional frailty* (De Witte et al., 2013b; De Roeck et al., 2018). The physical domain evaluates the general physical health (e.g., walking up a hill or stairs); the psychological domain assesses mood-disorders and emotional loneliness (e.g., feeling pressure); the social domain contains social loneliness and social support (e.g., there are enough people I feel close to); and the environmental domain evaluates conditions of inadequate housing using (e.g. my house is in a bad condition). Cognitive frailty was recently added to the CFAI and evaluates cognitive functioning (e.g., memory problems) (De Roeck et al., 2018). The Fried's phenotype of frailty (slow mobility, weakness, weight loss, decreased activities and exhaustion) (Fried et al., 2001) will be used to assess the *physical phenotype of frailty* as well as the questionnaire of Op het Veld et al. (2018). For weakness and slow mobility, 180 older participants will do the physical tests included in the Fried's phenotype of frailty. The *subjective feeling of frailty* will be assessed with a self-constructed question which explores to what extent the participant agrees with the statement 'I feel frail'. Older participants will also be asked to rate their subjective feeling of being frail on a scale from 0 to 10. *Resilience* will be measured by using the Connor-Davidson Resilience Scale (CD-RISC2), which is an abbreviated 2-item version of the original Scale (Vaishnavi, Connor, & Davidson, 2007). *Coping* will be measured by using 6 items (i.e., active coping, positive re- framing, acceptance, religion, emotional support and self-distraction) of the BRIEF Cope Carver scale (Carver, 1997). By proposing statements, older participants need to answer to what extent they would react like this in a stressful or difficult situation. *Help needed for activities in daily life* will be measured by asking if older participants need help with 8 activities of daily life (i.e., personal care, household tasks, personal displacements, administrative and financial management, social company and support, grocery shopping, chores and supervision), and to what extent the help they receive for these activities is sufficient. These questions are adapted from the questionnaire of the Belgian Ageing Studies (BAS) (De Donder et al., 2014). *Informal and formal care* will be assessed by asking older participants if they receive care from 7 informal (e.g., children, neighbors, friends) and 13 formal caregivers (e.g., home nursing), and if they are satisfied with the help they receive from these caregivers. These questions are adapted versions of the BAS-questionnaire (De Donder et al., 2014). *Medical care* will be measured by asking how many times the participants needed to go to a general practitioner, a hospital, residential setting and/or rehabilitation center over the past 6 months (day care/ overnight stay). These questions are adapted from the Health Interview Survey (Wetenschappelijk Instituut Volksgezondheid, 2013). In addition, the participants will be asked when they visited a general practitioner for the last time. Also, different aspects of the environment will be assessed. First, the *social environment* will be administered by using 3 items from the social cohesion dimension of the Neighborhood Scale (Mujahid, Roux, Morenoff, & Raghunathan, 2007). Second, the *physical environment* will be explored by using 4 items from the BAS-questionnaire (De Donder et al., 2014) as well as from the Neighborhood Environment Walkability Scale (Cerin, Saelens, Sallis, & Frank, 2006). In terms of participation, *leisure time* will be measured by using an adapted question with 8 items derived from the BAS questionnaire (De Donder et al., 2014). This question will examine how often the participants perform following activities: giving care or support, voluntary work, activities at home, sport activities outside a club, cultural activities, activities in an organization, going to a bar/restaurant/shopping center/trips, attend training. Also, *low-key social participation* will be examined by using 2 items from the questionnaire of Oswald and Konopik (2015). *Future perspective* will be assessed by using a self-constructed question and will explore to what extent the participant has things to look forward to. Finally, the occurrence of life-events will be assessed by using a shortened version (11 items) of the Geriatric Adverse Life Events Scale (GALES) (Devanand, Kim, Paykina, & Sackeim, 2002; Seematter-Bagnoud, Karmaniola, & Santos-Eggimann, 2010).

Additional measures

Several variables will be assessed in order to provide insight information concerning the study population, and to interpret outcomes of the study. These are the socio-demographic variables, assessed during the process of screening for eligibility: age, gender, country of birth, educational level, marital status and moved last 10 years (Dury et al., 2017; De Donder et al., 2014). Additionally, also nationality will be assessed as well as the socio-economic situation (net monthly household income) (De Donder et al., 2014).

The questionnaires will be available in Dutch and in French. Questions from existing instruments will be translated (if not already validated in the respective language) using a team translation approach called the Translation, Review, Adjudication, Pre-Testing and Documentation (TRAPD) translation model (Harkness & Round, 2017). Team approaches provide the richest output in options to choose from for translation. Another advantage of this method is the acquisition of balanced critique and a more fundamental choice between different versions (Guillemin, Bonbardier, & Beaton, 1993). In the TRAPD model, several translators will make independent parallel translations of the same questionnaire (Harkness & Round, 2017). Thereafter, the translators and translation re- viewers will go through the entire questionnaire discussing versions and agreeing on a final review version. The version produced trough discussion will move on to adjudication. The survey will also be screened by "Wablieft", an organization who will check the accessibility and clarity of the survey taking into account the target group, (possibly frail) older adults.

Table 4. SPIRIT diagram outlining schedule of enrolment, intervention and assessments for study participants

Time points		Enrolment	Baseline assessment T0	Intervention	Quantitative monitoring	Monthly follow-up	Study assessment T1	Qualitative evaluation
Introduction/ preparation	Screening eligibility criteria	x						
	Information letter	x						
	Informed consent	x						
Study groups	Experimental group		x	x	x	x	x	x
	Control group		x				x	x
	Care avoiders		x				x	x
	Group ≤ mild frail (CFAI-plus) or do not feel frail (subjective assessment of frailty)		x				x	x
	Informal caregivers							x
	Municipal health and social care professionals							x
Primary outcome measures	Quality of life		x				x	
	Meaning in life		x				x	
	Life satisfaction		x				x	
	Mastery		x				x	
	Community inclusion		x				x	
	Ageing well in place		x				x	
Secondary outcome measures (1)	Multidimensional frailty		x				x	
	Physical phenotype of frailty		x				x	
	Feeling frail		x				x	
	Resilience		x				x	
	Coping		x				x	
	Help needed for activities in daily life		x				x	
	Informal and formal care		x				x	

Time points		Enrolment	Baseline assessment T0	Intervention	Quantitative monitoring	Monthly follow-up	Study assessment T1	Qualitative evaluation
Secondary outcome measures (2)	Medical care		x				x	
	Leisure time		x				x	
	Neighborhood		x				x	
	Future perspective		x				x	
	Life evens		x				x	
Additional variables	Socio-demographic variables		x				x	
	Socio-economic situation		x				x	
Process measures	Amount of intended target group that participated in the second home visit/started the intervention				x			
	Amount and types of delivered intervention(s)				x			
	Number refuses, dropouts and completions				x			
	Logbook				x			
	Reasons for refusal/dropout					x		
	Satisfaction of intervention					x		
	Satisfaction D-SCOPE frailty program							x
	Experiences care/support processes							x
	Components that support or inhibit the implementing process of the D-SCOPE frailty program							x

Process evaluation

In order to evaluate the quality and sustainability of the D-SCOPE frailty program a quantitative questionnaire will be used during the intervention to measure the number of older adults that participated in the second home visit (1), started the intervention (2) and, dropped-out during the intervention (3). A professional from the social service of each municipality will also keep track of a logbook. In this logbook the amount of contacts in the intervention, the offered informal and formal care and support, satisfaction about the offered care and support and the problems encountered during the intervention will be registered. The reasons for refusal/dropout before the start as well as during the intervention will be evaluated as well.

In addition, after T1, in each municipality 3 focus groups will be organized: one with older adults who participated in one of the four groups, one with informal caregivers and one with professionals participating in the D-SCOPE frailty program. Because in complex interventions social or behavioral processes are difficult to explore using quantitative methods alone (Lewin, Glenton, & Oxman, 2009) the use of an additional qualitative research design will be helpful in providing valuable new insights. The goal is to determine the participant's opinions concerning the added value of the program and to identify components that support or inhibit the process of implementing the D-SCOPE frailty program. The focus groups will be held by a semi-structured interview schedule, developed following a literature review and input from the D-SCOPE consortium, consisting of researchers from different research areas from different universities:

- Satisfaction with the D-SCOPE frailty program
- Experiences of the care/support processes
- Identification of components that support or inhibit the process of implementing the D-SCOPE frailty program: the extent to which success factors or problems were encountered while applying the program.

2.8. Data gathering

Data on baseline characteristics, frailty, balancing factors and outcomes will be collected to evaluate the effect of the intervention with questionnaires at two points in time: T0 and T1 (6 months after inclusion). Participants in the study will concern all groups; the experimental group of the RCT, the control group of the RCT, older participants with no-to-low frailty

(CFAI-plus) or who do not feel frail (subjective assessment of frailty) and care avoiders. Trained volunteers or researchers will collect the T0 data. A professional from the social service of the municipality will receive all completed questionnaires and informed consents from the baseline assessment after the first home visit and will register the completed questionnaires in a specific designed computer program named Qualtrics. The research coordinator, who is responsible for the randomization to the control and experimental group, will be the person who can consult the results and will communicate to the municipality which respondents are randomized in the experimental group. The municipality will arrange that the experimental group receives a second home visit by a professional from the social service of the municipality, search an appropriate intervention and do the follow-up. After 6 months, trained volunteers and researchers will collect the T1 data. A professional from the social service of the municipality will again receive all completed questionnaires from the T1 assessment and will register them in the specific designed computer file. At the end, the research coordinator will consult the data.

2.9. Power analysis

As we have no clear view yet on all aspects, factors, scales, outcomes, statistical analyses, etc., it is not feasible to run detailed power analyses a priori. However, according to Cohen (Cohen, 1988) and when using the online a priori sample size calculator for independent sample t-tests (Soper, 2016); the minimum sample size per group (experimental as well as control group) with a probability level of .05, an anticipated Cohen's d effect size of 0.5 (medium) and a desired statistical power of 0.8 will be 64. To find differences with a small effect size (cohen's d = 0.2) between the 2 groups a total n of 788 (394 in each group) is required.

As is our longitudinal design is concerned, we have based our a priori estimation on a study of Fabricotti et al. (2013). They expect a 10% loss to follow up (due to mortality, re-housing, impossibility or unwillingness to participate further) between T0 and T1. By including 220 older adults in both the experimental and control group, they state that their sample is sufficient to detect changes. Assuming an average effect size of 0.5 and significance of 5%, this gives a power of 0.997. They further argue that if a small effect size is expected of 0.3 with a significance of 5%, this still supplies sufficient power at 0.837. Interfering variables will also play a role. At an average effect size (f2) of 0.15 and significance of 5%, assuming five independent variables, the power is 0.97. Even with 15 independent variables, the power remains sufficient at 0.856.

So, in sum, it was decided to aim for 900 community- dwelling older adults aged 60 years, equally divided over the municipalities Knokke-Heist, Ghent and Tienen in Flanders, Belgium; so 300 community-dwelling older adults will participate in each municipality.

2.10. Blinding

Older participants, interviewers performing the baseline assessment and researchers doing the outcome assessment and data analysis will be blinded to group allocation. It won't be possible to blind the research coordinator and municipal health and social care professionals performing the intervention to group allocation. Interviewers won't be blinded when doing the follow-up.

2.11. Analysis of the data

Effect evaluation

The experimental and control groups will be described at both time points with descriptive statistics. Similarity of characteristics between the two groups will be assessed by means of independent sample t-tests or chi-square tests. Differences in measurements between T0 and T1 will be assessed by means of repeated measures ANOVA's. In order to explore which combination of resources lead to a higher quality of life, meaning in life, life satisfaction, mastery, community inclusion and ageing well in place in frail, community-dwelling older adults, different interaction models with balancing factors as moderators will be tested. We will explore which balancing factors are moderators for having a good quality of life, meaning in life, life satisfaction, mastery, community inclusion and ageing well in place, despite being frail. We will explore the hypothesis that frail, older adults who have the adequate resources (positive frailty-balance) have a better chance for aforementioned positive outcomes than frail, older adults with a negative frailty-balance. For each measure, regression analyses will be performed with the T1 scores as the dependent variable, the research group (experimental vs. control) as independent variable of interest, and demographic variables and differences in baseline characteristics as co-variates. Multivariate analyses will be performed in order to answer the research questions.

Process evaluation

All qualitative interviews will be audio-recorded and transcribed verbatim. Interviews will be analyzed by the use of thematic content analysis. In order to increase the credibility of the findings, the coding frames and strategies will be subject to systematic review by the two principal investigators and refined through a process of consensus. Findings from each focus group will be analyzed separately to have a cross-sectional perspective, and only after separate analysis has taken place the focus groups will be combined for a comparative analysis. This generates cross-sectional descriptions of each municipality and enables a comparative view capturing similarities and differences between localities.

All quantitative data will be analyzed with SPSS (Field, 2009) and all qualitative data will be analyzed using the MAXQDA software package (Gibbs, 2007).

3. Discussion

In order to detect and prevent frailty worsening in community-dwelling older adults, a program on detection and prevention is needed, involving targeted case-finding, individualized assessment, tailor-made interventions and repeated short-term follow-up. In the upcoming years, the aging population will increase the challenges on health care systems and consequently the management of community care and support needs to be reconsidered. By introducing the D-SCOPE frailty program, we aim to provide an efficient structure for a timely and accurate detection of frailty-imbalance in community-dwelling older adults and for the organization and delivery of efficient and effective care and support.

Some challenges will be taken into account. Research indicates that the implementation of integrated care pro- grams is challenging and difficult (Kodner, 2003). For example, frail individuals who receive care and support often lose control over their own lives and receive little opportunity to shape their own care. Furthermore, when integrated care interventions are successfully implemented in one specific setting, the dissemination on a wider scale remains challenged (Johri, Beland, & Bergman, 2003). Several activities were and will continue to be organized to face these challenges. The D-SCOPE frailty program has been designed in close collaboration with different actors specialized in care and support for older adults, which along with the process evaluation and future protocol meetings are intended to ensure the quality and sustainability of the program.

The D-SCOPE program has a number of strengths, which makes the study relevant for science and practice. First, this program will not focus of the total older population of the municipality but will target older adults with an increased risk for frailty. This targeted case-finding will permit the organization of well-coordinated, targeted and comprehensive home and community care, which is a key factor to maintain frail, older adults at home (Giannini et al., 2007). Second, this program will create a tailored delivery system of care and support by the use of a frailty-balance approach. Two individuals with the same frailty may have a totally different quality of life, autonomy, etc. due to their strengths, re- sources and skills accumulated or lost over time (Grundy, 2006). The D-SCOPE program acknowledges the fact that need of care, support and empowerment is highly personal (de Blok et al., 2009). Moreover, current frailty instruments often lead to false positives (Pijpers, Ferreira, Stehouwer, Nieuwenhuijzen, & Kruseman, 2012). With the development of a frailty-balance instrument "diagnostic" accuracy can improve as only those older adults who are in need of care and/or support will be included in an integrated care and support trajectory.

In summary, the D-SCOPE program will contribute to the creation of a continuum of care and support for frail, older adults who often remain undetected. It will enhance the organization and transfer of care and support, which will have advantages for the individuals as well as for society. Specifically, the study is expected to show positive results on the quality of life, life satisfaction, meaning in life, autonomy and community inclusion of frail, community-dwelling older adults as a consequence of tailor-made interventions.

References

Ament, B. H. L., de Vugt, M. E., Verhey, F. R. J., & Kempen, G. I. J. M. (2014). Are physically frail older persons more at risk of adverse outcomes if they also suffer from cognitive, social, and psychological frailty? *European Journal of Ageing*, *11*(3), 213-219. doi: 10.1007/ s10433-014-0308-x

Armstrong, J. J., Stolee, P., Hirdes J. P., & Poss, J. W. (2010). Examining three frailty conceptualizations in their ability to predict negative outcomes for home-care clients. *Age and Ageing*, *39*(6), 755-758. doi: 10.1093/ageing/afq121

Baltes, P. B., & Smith, J. (2003). New frontiers in the future of aging: From successful aging of the young old to the dilemmas of the fourth age. *Gerontology*, *49*(2), 123-135. doi: 10.1159/000067946

Belfius. (2007). *Lokale financiën. Sociaaleconomische typologie van de gemeenten*. Retrieved on 2 July 2017, from https://www.belfius.be/publicsocial/NL/Media/Typologie_NEW_nl_tcm_31-36262.pdf

Bergman, H., Ferrucci, L., Guralnik, J., Hogan, D. B., Hummel, S., Karunananthan, S., et al. (2007). Frailty: An emerging research and clinical paradigm—Issues and controversies. *The Journals of Gerontology: Series A*, *62*(7), 731–737. doi: 10.1093/ gerona/62.7.731

Bolin, K., Lindgren, B., & Lundborg, P. (2008). Informal and formal care among single-living elderly in Europe. *Health Economics*, *17*(3), 393-409. doi: 10.1002/hec.1275

Buntinx, F., Paquay, L., Fontaine, O., Ylieff, M., & De Lepeleire, J. (2004). Options for a new procedure for determining care needs in Belgium: an initial exploration. *Archives of Public Health*, *62*(3-4), 173-184.

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, *4*(1), 92-100. doi: 10.1207/s15327558ijbm0401_6

Cerin, E., Saelens, B. E., Sallis, J. F., & Frank, L. D. Neighborhood environment walkability scale: Validity and development of a short form. *Medicine & Science in Sports & Exercise*, *38*(9), 1682-1691. doi: 10.1249/01.mss.0000227639.83607.4d

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. Hillsdale, NJ: Lawrence Earlbaum Associates.

Collard, R. M., Boter, H., Schoevers, R. A., & Oude Voshaar, R. C. (2012). Prevalence of frailty in community-dwelling older persons: A systematic review. *Journal of the American Geriatrics Society*, *60*(8), 1487-1492. doi: 10.1111/j.1532-5415.2012.04054.x

Colombo, F., Llena-Nozal, A., Mercier, J., & Tjadens, F. (2011). *Help wanted? Providing and paying for long-term care: OECD Health Policy Studies*. Paris: OECD Publishing.

de Blok, C., Meijboom, B., Luijkx, K., & Schols, J. (2009). Demand-based provision of housing, welfare and care services to elderly clients: From policy to daily practice through operations management. *Health Care Analysis*, *17*(1), 68-84. doi: 10.1007/s10728-008-0095-7.

De Donder, L., De Witte, N., Verté, D., Dury, S., Buffel, T., Smetcoren, A.-S., Brosens, D., & Verté, E. (2014). Developing evidence-based age-friendly policies: a participatory research project. *Research Methods Cases*. London: SAGE. doi: 10.4135/978144627305013508507

De Roeck, E. E., Dury, S., De Witte, N., De Donder, L., Bjerke, M., De Deyn, P. P., et al. (2018). CFAI-plus: adding cognitive frailty as a new domain to the comprehensive frailty assessment instrument. *International Journal of Geriatric Psychiatry, 33*(7), 941-947. doi: https://doi.org/10.1002/gps.4875

De Roeck, E. E., Engelborghs, S., & Dierckx, E. (2016a). Next generation brain health depends on early Alzheimer disease diagnosis: from a timely diagnosis to future population screening. *Journal of the American Medical Directors Association, 17*(5), 452-453. doi: 10. 1016/j.jamda.2016.02.015.

De Roeck, E., Ponjaert-Kristoffersen, I., Bosmans, M., De Deyn, P. P., Engelborghs, S., & Dierckx, E. (2016b). Are depressive symptoms in mild cognitive impairment predictive of conversion to dementia? *International Psychogeriatrics, 28*(6), 921-928. doi: 10.1017/S1041610215002409

Devanand, D. P., Kim, M. K., Paykina, N., & Sackeim, H. A. (2002). Adverse life events in elderly patients with major depression or dysthymic disorder and in healthy-control subjects. *The American Journal of Geriatric Psychiatry, 10*(3), 265-274. doi: 10.1097/ 00019442-200205000-00005.

De Witte, N., Buffel, T., De Donder, L., Dury, S., & Verté, D. Care shortages in later life: The role of individual and contextual variables in Flanders, Belgium. *International Journal of Social Sciences and Humanity Studies, 2*(1), 111-118.

De Witte, N., De Donder, L., Dury, S., Buffel, T., Verté, D., & Schols, J. (2013a). A theoretical perspective on the conceptualisation and usefulness of frailty and vulnerability measurements in community dwelling older adults. *Aporia: the Nursing Journal, 5*(1), 13-31.

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Schols, J., et al. (2013b). The comprehensive frailty assessment instrument: Development, validity and reliability. *Geriatric Nursing, 34*(4), 274-281. doi: 10.1016/j.gerinurse.2013.03.002

Diener, E., Emmons, R.A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment, 49*(1), 71-75. doi: 10.1207/s15327752jpa4901_13

Duppen, D., van der Elst, M. C. J., Dury, S., Lambotte, D., De Donder, L., & D-SCOPE. (2017). The social environment's relationship with frailty: Evidence from existing studies. *Journal of Applied Gerontolgy*. doi: 10.1177/0733464816688310

Dury, S., De Roeck, E., Duppen, D., Fret, B., Hoeyberghs, L., Lambotte, D., et al. (2017). Identifying frailty risk profiles of home-dwelling older people: focus on sociodemographic and socioeconomic characteristics. *Aging & Mental Health, 21*(10), 1031-1039. doi: 10.1080/13607863.2016.1193120.

Dury, S., Dierckx, E., van der Vorst, A., van der Elst, M., Fret, B., Duppen, D., et al. (2018). Detecting frail, older adults and identifying their strengths: results of a mixed-methods study. *BMC Public Health*, *18*, 191. doi: 10.1186/ s12889-018-5088-3

Espinoza, S., & Walston, J. D. (2005). Frailty in older adults: Insights and interventions. *Cleveland Clinic Journal of Medicine*, *72*(2), 1105-1112.

Fabbricotti, I. N., Janse, B., Looman, W.M., de Kuijper, R., van Wijngaarden, J. D. H., & Reiffers, A. (2013). Integrated care for frail elderly compared to usual care: a study protocol of a quasi-experiment on the effects on the frail elderly, their caregivers, health professionals and health care costs. *BMC Geriatrics*, *13*, 31. doi: 10.1186/1471-2318-13-31

Field, A. (2009). *Discovering statistics using SPSS. 3rd ed*. London: SAGE Publications Ltd.

Fret, B., Lambotte, D., Van Regenmortel, S., Dury, S., De Witte, N., Dierckx, E., et al. (2017). Socio-demographic, socio-economic and health need differences between types of care use in community-dwelling older adults. *International Journal of Care and Caring*, *1*(3), 351-366. doi: 10.1332/ 239788217X15027193795897

Fried, L. P., Tangen, C. M., Walston, J., Newman, A. B., Hirsch, C., Gottdiener, J., et al. (2001). Frailty in older adults: evidence for a phenotype. *The Journals of Gerontology: Series A*, *56*(3), M146-M157. doi: 10.1093/gerona/56.3.M146

Giannini, R., Petazzoni, E., Savorani, G., Galletti, L., Piscaglia, F., Licastro, F., et al. (2007). Outcomes from a program of home care attendance in very frail elderly subjects. *Archives of Gerontology and Geriatrics*, *44*(2), 95-103. doi: 10.1016/j.archger.2006.03.002

Gibbs, G. (2007). *Analyzing qualitative data*. London: SAGE Publications Ltd.

Gobbens, R. J. J., & van Assen, M. A. L. M. (2014). The prediction of quality of life by physical, psychological and social components of frailty in community-dwelling older people. *Quality of Life Research*, *23*(8), 2289-2300. doi: 10.1007/s11136-014-0672-1

Guillemin, F., Bombardier, C., & Beaton, D. (1993). Cross-cultural adaptation of health-related quality of life measures: Literature review and proposed guidelines. *Journal of Clinical Epidemiology*, *46*(12), 1417-1432. doi: 10.1016/0895-4356(93)90142-N

Grenier, A. (2007). Constructions of frailty in the English language, care practice and the lived experience. *Ageing & Society*, *27*(3), 425-445. doi: 10.1017/ S0144686X06005782

Grundy, E. (2006). Ageing and vulnerable older people: European perspectives. *Ageing & Society*, *26*(1), 105-134. Doi: 10.1017/S0144686X05004484

Hansson, R. O., Robson, S. M., & Limas, M. J. (2001). Stress and coping among older workers. *Work, 17*(3), 247-256.

Harkness, J. A. (2008). *Round 4 ESS translation strategies and procedures*. Retrieved on 22 January 2017, from http://www.europeansocialsurvey.org/docs/round4/methods/ESS4_translation_guidelines.pdf

Jacobs, M., Van Tilburg, T., Groenewegen, P., & Broese van Groenou, M. (2016). Linkages between informal and formal caregivers in home-care networks of frail older adults. *Ageing & Society*, *36*(8), 1604-1624. doi: 10.1017/S0144686X15000598

Johri, M., Beland, F., & Bergman, H. (2003). International experiments in integrated care for the elderly: A synthesis of evidence. *International Journal of Geriatric Psychiatry*, *18*(3), 222-235. doi: 10.1002/gps.819

Kodner, D.L. (2003). Consumer-directed services: lessons and implications for integrated systems of care. *International Journal of Integrated Care*, *3*(2). doi: 10.5334/ijic.80

Kojima, G., Iliffe, S., Jivraj, S., & Walters, K. (2016). Association between frailty and quality of life among community-dwelling older people: A systematic review and meta-analysis. *Journal of Epidemiology & Community Health*, *70*(7), 716-721. doi: 10.1136/ jech-2015-206717

Lee, W.-J., Chen, L.-K., Peng, L.-N., Chiou, S.-T., & Chou, P. (2016). Personal mastery attenuates the adverse effect of frailty on declines in physical function of older people. A 6-year population-based cohort study. *Medicine (Baltimore)*, *95*(34), e4661-e4667. doi: 10.1097/MD.0000000000004661

Lee, D. R., Kawas, C. H., Gibbs, L., & Corrada, M. M. (2016). Prevalence of frailty and factors associated with frailty in individuals aged 90 and older: The 90+ study. *Journal of the American Geriatrics Society*, *64*(11), 2257-2262. doi: 10.1111/jgs.14317

Lewin, S., Glenton, C., & Oxman, A. D. (2009). Use of qualitative methods alongside randomised controlled trails of complex healthcare interventions: methodological study. *BMJ*, *339*, b3496. doi: 10.1136/bmj.b3496

Lette, M., Baan, C. A., van den Berg, M., & de Bruin, S. R. (2015). Initiatives on early detection and intervention to proactively identify health and social problems in older people: experiences from the Netherlands. *BMC Geriatrics*, *15*, 143. doi: 10.1186/s12877-015-0131-z

Löfqvist, C., Granbom, M., Himmelsbach, I., Iwarsson, S., Oswald, F., & Haak, M. (2013). Voices on relocation and aging in place in very old age. A Complex and Ambivalent Matter. *The Gerontologist*, *53*(6), 919-927. doi: 10.1093/geront/gnt034

McColl, M. A., Davies, D., Carlson, P., Johnston, J., & Minnes, P. (2001). The community integration measure: development and preliminary validation. *Archives of Physical Medicine and Rehabilitation*, *82*(4), 429-434. doi: 10.1053/apmr.2001.22195

Moons, D. (2016a). *Knokke-Heist*. Agentschap Binnenlands Bestuur & Studiedienst Vlaamse Regering.

Moons, D. (2016b). *Gent*. Agentschap Binnenlands Bestuur & Studiedienst Vlaamse Regering.

Moons, D. (2016c). *Tienen*. Agentschap Binnenlands Bestuur & Studiedienst Vlaamse Regering.

Mujahid, M. S., Roux, A. V. D., Morenoff, J. D., & Raghunathan, T. (2007). Assessing the measurement properties of neighborhood scales: From psychometrics to ecometrics. *American Journal of Epidemiology*, *165*(8), 858-867. doi: 10.1093/aje/kwm040

Nyweide, D. J., Anthony, D. L., Chang, C. H., & Goodman, D. (2011). Seniors' perceptions of health care not closely associated with physician supply. *Health Affairs*, *30*(2), 219-227. doi: 10.1377/hlthaff.2010.0602

Oswald, F., & Konopik, N. (2015). Impact of out-of-home activities, neighborhood and urban-related identity on well-being in old age. *Zeitschrift fur Gerontologie und Geriatrie*, *48*(5), 401-407. doi: 10.1007/s00391-015-0912-1

Op het Veld L. P. M., de Vet, H. C. W., van Rossum, E., Kempen, G. I. J. M., van Kuijk, S. M. J., & Beurskens, A. J. H. M. (2018). Substitution of Fried's performance-based physical frailty criteria with self- report questions. *Archives of Gerontology and Geriatrics*, *75*, 91-95. doi: 10.1016/j. archger.2017.11.009

Paulus, D., Van den Heede, K., & Mertens, R. (2012). *Position paper: Organisation of care for chronically ill patients in Belgium. Health Services Research (HSR).* Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE).

Pearlin, L. I., Nguyen, K. B., Schieman, S., & Milkie, M. A. (2007). The life-course origins of mastery among older people. *Journal of Health and Social Behavior*, *48*(2), 164-179. doi: 10. 1177/002214650704800205

Pijpers, E., Ferreira, I., Stehouwer, C. D., Nieuwenhuijzen, & Kruseman, A. C. (2012). The frailty dilemma. Review of the predictive accuracy of major frailty scores. *European Journal of Internal Medicine*, *23*(2), 118-123. doi: 10.1016/j.ejim.2011.09.003

Rockwood, K., Howlett, S. E., MacKnight, C., Beattie, B. L., Bergmann, H., Hébert, R., et al. (2004). Prevalence, attributes, and outcomes of fitness and frailty in community-dwelling older adults: Report from the Canadian study of health and aging. *The Journals of Gerontology: Series A*, *59*(12), 1310-1317. doi: 10.1093/gerona/59.12. 1310

Tindale, J., Denton, M., Ploeg, J., Lilie, J., Hutchison, B., Brazil, K., et al. (2011). Social determinants of older adults' awareness of community support services in Hamilton, Ontario. *Health and Social Care in the Community*, *19*(6), 661-672. doi: 10. 1111/j.1365-2524.2011.01013.x

Scharlach, A. (2012). Creating aging-friendly communities in the United States. *Ageing International*, *37*(1), 25-38. doi: 10.1007/s12126-011-9140-1

Seematter-Bagnoud, L., Karmaniola, A., & Santos-Eggimann, B. (2010). Adverse life events among community-dwelling persons aged 65-70 years: gender differences in occurrence and perceived psychological consequences. *Social Psychiatry and Psychiatric Epidemiology*, *45*(1), 9-16. doi: 10.1007/s00127-009-0035-3

Smetcoren, A.-S., De Donder, L., Dury, S., De Witte, N., Kardol, T., & Verté, D. (2017a). Refining the push and pull framework: identifying inequalities in residential relocation among older adults. *Ageing & Society*, *37*(1), 90-112. doi: 10.1017/ S0144686X15001026

Smetcoren, A.-S., Dury, S., De Donder, L., & Dierckx, E. (2017b). D-SCOPE: naar een positieve kijk op preventive bij kwetsbare ouderen. *Geron*, *19*(1), 35-38. doi: 10.1007/s40718-017-0010-0

Smetcoren, A.-S., Dury, S., De Donder, L., Dierckx, E., De Witte, N., Engelborghs, S., et al. (2018). Detectie en preventie van kwetsbaarheid: Op zoek naar risicoprofielen voor fysieke, psychische, sociale en omgevingskwetsbaarheid. *Tijdschrift voor Gerontologie en Geriatrie*, *49*(1), 1-11. doi: 10.1007/s12439-017-0241-5

Soper, D.S. (2016). *A-priori Sample Size Calculator for Student t-Tests*. Retrieved on 11 February 2017, from http://www.danielsoper.com/statcalc

Steger, M. F., Frazier, P., Oishi, S., & Kaler, M. (2006). The meaning in life questionnaire: assessing the presence of and search for meaning in life. *Journal of Counseling Psychology*, *53*(1), 80-93. doi: 10.1037/0022-0167.53.1.80

Vaishnavi, S., Connor, K., & Davidson, J. R. T. (2007). An abbreviated version of the Connor-Davidson resilience scale (CD-RISC), the CD-RISC2: Psychometric properties and applications in psychopharmalogical trials. *Psychiatry Research*, *152*(2-3), 293-297. doi: 10.1016/j.psychres.2007.01.006

van der Vorst, A., Zijlstra, G. A. R., De Witte, N., Duppen, D., Stuck, A. E., Kempen, G. I. J. M., et al. (2016). Limitations in activities of daily living in community-dwelling people aged 75 and over: a systematic literature review of risk and protective factors. *PLoS One*, *11*(10), e0165127. doi: 10.1371/journal.pone.0165127

van der Vorst, A., Zijlstra, G. A. R., De Witte, N., Vogel, R. G. M., Schols, J. M. G. A, Kempen, G. I. J. M, et al. (2017). Explaining discrepancies in self-reported quality of life in frail older people: a mixed-methods study. *BMC Geriatrics*, *17*, 251. doi: 10. 1186/s12877-017-0641-y

Verkerk, M. (2001). The care perspective and autonomy. *Medine, Health Care and Philosophy*, *4*(3), 289-294. doi: 10.1023/A:1012048907443

Viana, J. U., Silva, S. L. A., Torres, J. L., Dias, J. M. D., Pereira, L. S. M., & Dias, R. C. (2013). Influence of sarcopenia and functionality indicators on the frailty profile of community-dwelling elderly subjects: A cross-sectional study. *Brazilian Journal of Physical Therapy*, *17*(4), 373-381. doi: 10.1590/S1413-35552013005000102

Wetenschappelijk Instituut Volksgezondheid. (2013). *Health Interview Survey 2013*. Retrieved on 5 January 2017, from https://his.wiv-isp.be/nl/SitePages/Vragenlijsten.aspx

Willemé, P. (2010). *The Long-Term Care System for the Elderly in Belgium. ENEPRI Research Report n°70*. Retrieved on 5 January 2017, from http://www.ancien-longtermcare.eu/sites/default/files/ENEPRI%20RR%2070%20ANCIEN%20Belgian.pdf

World Health Organization. (1996). *WHOQOL-BREF Introduction, administration scoring and generic version of the assessment*. Retrieved on 5 January 2017, from http://www.who.int/mental_health/media/en/76.pdf?ua=1

Yang, Z., Norton, E. C., & Stearns, S. C. (2003). Longevity and health care expenditures: The real reasons older people spend more. *The Journals of Gerontology: Series B*, *58*(1), S2-S10. doi: 10.1093/geronb/58.1.S2

References

Balcazar, F. E., Taylor, R. T., Kielhofner, G. W., Tamley, K., Benziger, T., Carlin, N., & Johnson, S. (2004). Community development: Enhancing the knowledge base through participatory action research. In L. A. Jason, C. B. Keys, Y. Suarez-Balcazar, R. R. Taylor, & M. Davis (Eds.), *Participatory community research: Theories and methods in action* (pp. 221–226). London: APA.

Campbell, D. T., & Fiske, D. W. (1959). Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychological Bulletin*, *56*(2), 81-105.

Christensen, L. B., Johnson, R. B., & Turner, L. A. (2011). *Research methods, design, and analysis.* Boston: Pearson Education, Inc.

De Donder, L., De Witte, N., Verté, D., Dury, S., Buffel, T., Smetcoren, A.-S., et al. (2014). Developing evidence-based age-Friendly policies: A participatory research project. *Research Methods Cases*. London: SAGE. doi: 10.4135/978144627305013508507

Denzin, N. K. (1978). *The research act: A theoretical introduction to sociological methods*. New York: Praeger.

De Roeck, E. E., Dury, S., De Witte, N., De Donder, L., Bjerke, M., De Deyn, P. P., et al. (2018). CFAI-Plus: Adding cognitive frailty as a new domain to the comprehensive frailty assessment instrument. *International Journal of Geriatric Psychiatry*, *33*(7), 941-947. doi: 10.1002/gps.4875

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Schols, J., et al. (2013). The Comprehensive Frailty Assessment Instrument: Development, validity and reliability. *Geriatric Nursing*, *34*(4), 274-281. doi: 10.1016/j.gerinurse.2013.03.002

Dury, S., De Roeck, E., Duppen, D., Fret, B., Hoeyberghs, L., Lambotte, D., et al. (2017). Identifying frailty risk profiles of home-dwelling older people: focus on sociodemographic and socioeconomic characteristics. *Aging & Mental Health*, *21*(10), 1031-1039. doi: 10.1080/13607863.2016.1193120

Dury, S., Dierckx, E., van der Vorst, A., van der Elst, M., Fret, B., Duppen, D., et al. (2018). Detecting frail, older adults and identifying their strengths: results of a mixed-methods study. *BMC Public Health*, *18*, 191. doi: 10.1186/s12889-018-5088-3

Dierckx de Casterlé, B., Gastmans, C., Bryon, E., Denier, Y. (2012). QUAGOL: A guide for qualitative data analysis. *International Journal of Nursing Studies*, *49*(3), 360–371. doi: 10.1016/j.ijnurstu.2011.09.012

Flemish Government. (2004). *Decreet houdende de stimulering van een inclusief Vlaams ouderenbeleid en de beleidsparticipatie van ouderen*. Retrieved from http://www.etaamb.be/nl/decreet-van-30-april-2004_n2004036148.html

Foss, C., & Ellefsen, B. (2002). The value of combining qualitative and quantitative approaches in nursing research by means of method triangulation. *Journal of Advanced Nursing*, *40*(2), 242-248. doi: 10.1046/j.1365-2648.2002.02366.x

Henderson, J., & Forbat, L. (2002). Relationship-based social policy: Personal and policy constructions of 'care'. *Critical Social Policy*, *22*(4), 669–687. doi: 10.1177/02610183020220040601

Jason, L. A., Keys, C. B., Suarez-Balcazar, Y., Taylor, R. R., & Davis, M. (2004). *Participatory community research. Theories and methods in action*. London, England: APA. doi: 10.1037/10726-000

Johson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, *33*(7), 14-26. doi: 10.3102/0013189X033007014

Johson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, 1(2), 112-133. doi: 10.1177/1558689806298224

Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: Theorizing intersections of formal and informal care. *Journal of Aging Studies*, *27*(1), 15-29. doi: 10.1016/j.jaging.2012.10.002

Lambotte, D., De Donder, L., De Roeck, E.E., Hoeyberghs, L., van der Vorst, A., Duppen, D., et al. (2018). Randomized controlled trial to evaluate a prevention program for frail community-dwelling older adults: a D-SCOPE protocol. *BMC Geriatrics*, *18*, 194. doi: 10.1186/s12877-018-0875-3

Reason, P., & Bradbury, H. (2008). *Handbook of action research: Participative inquiry and practice.* London, England: SAGE.

Silva, E., Warde, A., & Wright, D. (2009). Using mixed methods for analysing culture: The cultural capital and social exclusion project. *Cultural Sociology*, *3*(2), 299–316. doi: 10.1177/1749975509105536

Stringer, E.T. (2007). *Action research. 3rd ed.* London: SAGE.

Part 3

Care convoys of frail, community-dwelling older adults

Chapter 5. Relational aspects of mastery for frail, older adults: The role of informal caregivers in the care process

Manuscript accepted for publishing

Lambotte, D., Kardol, M. J. M., Schoenmakers, B., Fret, B., Smetcoren, A.-S., De Roeck, E. E., Van der Elst, M., De Donder, L., & the D-SCOPE Consortium. (2018). Relational aspects of mastery for frail, older adults: The role of informal caregivers in the care process. *Health and Social Care in the Community*. doi: 10.1111/hsc.12676

Abstract

Frail, older care recipients are often thought of as individuals with a decreased mastery of everyday life skills. Various authors have proposed to acknowledge a relational dimension of mastery, defined as the ability to maintain control over one's life with the help of others. This study explores how frail, older adults experience relational aspects of mastery and the role their informal caregivers play in maintaining these aspects of mastery over the care process. Qualitative interviews (*N* = 121) were conducted in 2016 with potentially frail, community-dwelling older adults participating in the Detection, Support and Care for Older people: Prevention and Empowerment (D-SCOPE) project. A secondary analysis of 65 interviews reveals that, according to frail, older adults, informal caregivers contribute in various ways to the preservation of their mastery. This differs across the four elements of care: caring about (attentiveness), taking care of (responsibility), care-giving (competence) and care-receiving (responsiveness). However, in some cases, older adults experienced a loss of mastery; for example, when informal caregivers did not understand their care needs and did not involve them in the decision, organisation and provision of care. A relational dimension of mastery needs to be acknowledged in frail, older care recipients since stimulating mastery is a crucial element for realising community care objectives and person-centred and integrated care.

Key words

Older adults; informal care; relational aspects of mastery; qualitative research; secondary analysis

1. Introduction

European countries are searching for innovative ways to organise and provide care and support in order to deal with the growing needs of an ageing population (Campbell et al., 2016). Therefore, current health and social care policies in Western Europe have emphasised deinstitutionalisation and support ageing in place by organising support and care resources to help older adults remain in their own homes and community (Dury, 2018; Means, Richards, & Smith, 2008). Ageing in place also reflects the preferences of older adults to live at home for as long as possible (Stones & Gullifer, 2016), even up to the stage when they become frail and need additional care and support (Löfqvist et al., 2013). A variety of formal (home) care services are provided, and informal caregivers are encouraged to support frail, older adults (Kröger & Bagnato, 2017). However, as a consequence of budgetary cuts in institutional care and home care services, informal caregivers are compelled to increasingly take responsibility for the care of their loved-ones (Kröger & Bagnato, 2017). Amongst others, the Flemish informal care plan stimulates older adults to access their social network before using formal home care services (Vandeurzen, 2016). Consequently, stimulating mastery in older adults has emerged as a major theme in a number of recent policies and studies (Claassens et al., 2016; Janssen, Abma, & Van Regenmortel, 2012).

Mastery refers to a person's ability to control circumstances in his or her life (Pearlin & Schooler, 1978), and is often assumed to be related to self-determination and individual choices (Janssen et al., 2012). Research has demonstrated a wide range of positive outcomes for mastery: a greater sense of mastery (a) attenuates the adverse effects of frailty (Lee, Chen, Peng, Chiou, & Chou, 2016); (b) is related to lower healthcare use (Ezeamama et al., 2016); and (c) is related to less depressive symptoms (Nicolaisen, Moum, & Thorsen, 2017). However, Janssen et al. (2012) argue that the classical view of mastery is not sufficient when studying frail, older adults and suggest a relational dimension to mastery; namely, the important role of significant others in supporting frail, older adults to maintain mastery over their lives. The classical approach, criticised by various care ethicists, suggests that individuals in care situations, and thus dependent individuals, cannot be autonomous (Tronto, 1993; Verkerk, 2001). This new, relational conceptualisation of mastery acknowledges issues of dependency and care relationships (Holstein, Parks, & Waymack, 2011; Perkins, Ball, Whittington, & Hollingsworth, 2012), and includes the ability to remain in control over one's life with help of others (Janssen et al., 2012).

When looking at care relationships, Tronto (1993) describes the care process as an integrated, holistic process and makes a distinction between four elements of care. Good care implies, in each element, a specific moral quality. The four elements of care (and their moral quality) are caring about (attentiveness), taking care of (responsibility), care-giving (competence) and care-receiving (responsiveness). Several studies used this framework in order to gain a better understanding of care processes in older adults (e.g. Clancy & Mahler, 2016; Grigorovich, 2016; Keyes, Webber, & Beveridge, 2015). The framework has been used in both residential and home settings, and for specific groups of older adults such as older lesbian and bisexual women.

This study explores how frail, older care recipients experience relational aspects of mastery and the role of their informal caregivers in maintaining these aspects of mastery within the context of four elements of care: caring about, taking care of, care-giving, and care-receiving (Tronto, 1993). The involvement of older adults within the care situation has been addressed in studies substantially focusing on relationships with formal care providers (e.g. Gregory, Mackintosh, Kumar, & Grech, 2017; José, Barros, Samitca, & Teixeira, 2016). However, informal caregivers are also important actors to stimulate mastery in frail, older adults (Holroyd-Leduc et al., 2016). Informal caregivers play an essential role in arranging and managing the continuity of care (Willemse et al., 2016). The complexity of the needs of care recipients influences the relationship with their informal caregivers and the care situation varies depending on, amongst others, the degree of autonomy and control care recipients have (Barrett, Hale, & Butler, 2014).

The current study investigates two research questions:

1. How do frail, older adults experience relational aspects of mastery, throughout the four elements of care?
2. How do frail, older adults experience the role of their informal caregivers in maintaining relational aspects of mastery over the four elements of care?

2. Methods

2.1. Data collection

In order to answer the aforementioned research questions, this study undertook a secondary analysis of qualitative data collected from the project Detection, Support and Care for Older people: Prevention and Empowerment (D-SCOPE) (Dury et al., 2018). The D-SCOPE project explores strategies for proactive detection of community-dwelling older adults at risk for frailty in order to guide them towards appropriate care and support, with a strong focus on empowerment. The Ethical Commission Human Sciences of the Vrije Universiteit, Brussel, approved the study (file number ECHW_031).

The original qualitative data collection comprised 121 in-depth interviews with community-dwelling older adults (60+) at risk for frailty. The in-depth interviews were conducted during the spring of 2016 in the Flemish region of Belgium and in Brussels and took place in participants' homes. The aim of the qualitative study was to collect information on participants' experiences, level of frailty, and on concepts such as mastery, care and support, and quality of life. Older participants were included in the study based on the following risk profiles for frailty: age, gender, marital status, level of education, household income, relocation in previous 10 years, and country of birth (Dury et al., 2017). Exclusion criteria and drop-outs were hospitalisation and any state that interfered with a good understanding of the questions (e.g. too exhausted to answer, or not being able to provide adequate answers). Also, older adults who received a dementia diagnosis, as determined by a doctor (specialist - geriatrician) were excluded.

The present study used qualitative data of participants who reported having a primary, informal caregiver (family member, friend, or neighbour) and who scored medium-to-high frail on at least one of the five domains of the Comprehensive Frailty Assessment Instrument Plus (CFAI-Plus) (De Roeck et al., 2018). The CFAI-Plus is an extended version of the CFAI, a self-assessment instrument which measures four domains of frailty: physical, psychological, social, and environmental frailty (De Witte et al., 2013a; De Witte et al., 2013b). De Roeck et al. (2018) added cognitive frailty to the CFAI, resulting in the CFAI-Plus. Based on the results of the CFAI-Plus, older adults were grouped into 1) not-to-low frail, 2) low-to-medium frail, and 3) medium-to-high frail, for each domain of frailty (De Roeck et al., 2018). Older adults who indicated to receive informal care during the interviews and who were classified in the third group for at least one of the five domains of the CFAI-Plus (De Roeck et al., 2018) were included in this study.

2.2. Interview scheme

Participants were informed about the voluntary nature of their involvement in the research project, their right to refuse to participate, and the confidentiality of their responses. Once the participants signed the informed consent form, trained researchers administered a quantitative questionnaire, and a qualitative, in-depth interview in the language of the participant's choice. Most of the interviews were conducted in Dutch or French by one of the researchers. In order to achieve maximum participation of participants who did not speak those languages, an interpreter attended the interviews when necessary.

The data used in this study originated from following questions on the interview scheme:

1. How does your experience of frailty have an effect on your care and support?
2. To what extent does frailty control the things happening in your life?
    a. How can you maintain mastery over your life? What do you need for this?
3. What should an older person do, have, or need to maintain his/her quality of life when becoming frail?
    a. Which role does your informal caregiver have?
4. What were the highlights and what were the low points in life during the past year? Did changes occur?

The interview scheme was developed by researchers specialising in gerontology and/or frailty from several disciplines (e.g. psychology, geriatric medicine, educational sciences, etc.) and was approved by a panel of experts from the D-SCOPE project to ensure the content validity of the interviews (Boeije, 2010).

The interviewers were trained before conducting the interviews. Several scenarios were developed in order to address potential difficulties and all researchers received a list of definitions explaining the terms used in the questionnaire. This list was used when the participants did not understand the questions.

All interviews were digitally recorded and transcribed verbatim in the language in which the interviews were conducted (Dutch or French). Regarding the interviews in the presence of an interpreter, only the answers as translated by the interpreter were transcribed. All data were anonymised.

2.3. Data analysis

A secondary analysis using thematic (content) techniques was conducted on the data and incorporated both deductive, concept-driven coding, and inductive, data-driven coding (Cho & Lee, 2014; Fereday & Muir-Cochrane, 2006; McGraw et al., 2017). For the deductive coding, a codebook was developed from the research literature. Resulting from this Tronto's four elements of care were applied as main labels: caring about, taking care of, care-giving and care-receiving (Tronto, 1993).

Tronto's four elements of care (and their related moral quality) (Tronto, 1993)

- Caring about (attentiveness): noticing the need for care
- Taking care of (responsibility): the commitment someone makes to the needs established in the earlier stage
- Care-giving (competence): providing the care and support needed in order to meet the care needs
- Care-receiving (responsiveness): the care receiver reacts in a certain way to the help provided. Respondents' reactions are an important aspect of the care process as it allows for observers to assess if the provided care and/or support meets the needs of the older individual.

Within this template, inductive coding took place for the creation of sublabels in the main labels concerning care recipients' experiences of relational aspects of mastery and the role of their informal caregivers in the preservation of these aspects of mastery. This approach made it possible to answer the aforementioned research questions while allowing for themes to emerge directly from the data. The main researcher of the study conducted the secondary analysis. The categories, codes and results were discussed in-depth with the other investigators and refined through a process of consensus (for example to encounter difficulties related to the choices to code participants' experiences in which element of care).

All interviews were coded and analysed using the software program MAXQDA, designed to facilitate thematic content analysis (Oliveira, Bitencourt, Teixeira, & Santos, 2013).

3. Results

Table 5 provides an overview of the characteristics of the participants. The average age of the participants was 79.9 years. The majority were women (N = 42) and widowed (N = 43). 12 participants had a migration background. Participants were often medium-to-high frail on different domains: 27 participants were physically medium-to-high frail, 52 participants were cognitively medium-to-high frail, 20 participants were psychologically medium-to-high frail, 10 participants were socially medium-to-high frail and 14 participants were environmentally medium-to-high frail.

Table 5. Characteristics of the participants (N = 65)

Characteristics		Participants
Age		Mean 79.9 years (sd 8.7) (range 60-95 years)
Gender	Men	23
	Women	42
Marital status	Married	14
	Never married	2
	Divorced	6
	Widowed	43
Migration background	Yes	12
	No	53
Medium-to-high frail according to the domain of frailty	Physical	27
	Cognitive	52
	Psychological	20
	Social	10
	Environmental	14

The interviews revealed that the participants received care and support from various, informal caregivers: family members like their spouse, children, and also friends and neighbours. They also received help for various activities such as home care, administration, or grocery shopping. Informal care often exceeded these usual care tasks with carers making house modifications, providing social and emotional support, and encouraging older adults to go outdoors. Within these activities, participants often experienced (more, or less) mastery due to the role of their informal caregivers in one or more elements of care (Tronto, 1993). Participants explained how they were afraid to lose their abilities and emphasised the significance of maintaining their autonomy. They often appreciated the relational aspects of their mastery with their informal caregivers because they felt less restricted and more in control of their daily lives.

3.1. Caring about: attentiveness

For the participants, relational aspects of mastery in this element contained awareness and recognition about care needs which were disclosed through interaction with others. Participants explained how they became aware of their care and support needs by conversing with their informal caregivers. Participants described how the informal caregivers observed the situation, discussed with them their care needs, and gave advice. One older woman explained how she decided to get surgery as a result of interacting with her daughter. She said: 'I got eye surgery, cataract. I used to have glasses. It is my daughter who recommended me to go to the oculist. She noticed I was reading the newspaper with a magnifying glass' (Woman, 89 years, widowed).

Participants claimed that their informal caregivers sometimes misinterpreted their care needs and helped in the wrong way. They did not always agree with the attentiveness of their informal caregivers. One older man explained how his children drew the wrong conclusions after finding empty boxes of medications:

They [children] once placed me in the hospital. I took Valium then. I kept all the empty boxes in a pack of cigarettes and I put that under my pillow. I took four Valiums, but they thought I took 16 of them. And they took me to the emergency. I said, "What is the problem now"? [They said] "16 Valiums, do you want to die"? I said, "I did not take 16 Valiums, I only took four". Then I had to stay in the psychiatric centre for three days (Man, 60 years, widowed).

3.2. Taking care of: responsibility

According to the participants, different relational aspects of mastery in the element *taking care of,* occurred. First, it involved the decision and organisation of care and support in interaction with their informal caregivers. Participants explained they consulted their informal caregivers and discussed with them care possibilities or vice versa.

One participant said: My husband died years ago and they [children] noticed I was sad. So, my daughter spoke to me saying “I will ask for three months, three months in a short stay residential facility”, and I said yes. This was a good idea given my situation (Woman, 84 years, widowed).

Second, besides discussing care options, participants also asked for help from their informal caregivers. However, they took into account the limitations of informal care (e.g. time restrictions, distance, etc.) when asking for help and explained they understood that informal care could not be requested at all time, and for everything. Informal caregivers also spontaneously offered help to the participants.

Conversely, participants were not always involved by their informal caregivers in the decision-making and organisation of care and support. Participants explained how they themselves completely surrendered decision-making and did not want to be involved because they found it too difficult to make decisions. They were satisfied that their informal caregivers took responsibility without consulting them. As a participant expressed: ‘I don’t make decisions anymore. I aged. My reasoning process is not going well. I am not well informed about things. I leave this to the children’. When the interviewer asked if the participant left it to the children to make the decisions, the participant answered: ‘Oh yes, and they even make my signature’ (Woman, 91 years, widowed).

In some cases, participants were not asked to be involved in the decision and organisation of their care and support at all. This resulted in help that was not needed or did not match the wishes of the participants, and thus was not appreciated. Some of the older adults eventually accepted the help imposed on them by their informal caregivers. Some even became pleased to receive the organised help. One participant, for example, explained she did not want to move to a service flat but now liked to live there because of the social contacts saying (about leaving the apartment): ‘In fact, I did not really like moving out. But the children felt it was necessary. And it was time to register for a nursing home…’ When asked by the interviewer what turned something that at first was negative into something positive, the participant answered: ‘the social contacts. For example, all residents were reunited again, and we needed to introduce ourselves. I liked that’ (Woman, 78 years, divorced).

3.3. Care-giving: competence

Participants described mastery within this element as a relational activity by explaining how they were involved in the care and support activities by their informal caregivers. Participants explained they were supported in a manner such that they could maintain their independence. Ideally, older persons wanted to do things themselves. If this was not possible, they were happy to ask for advice or help (e.g. on financial matters) from their informal caregivers. Various activities of daily life such as grocery shopping, gardening, and cooking were also performed together. Participants valued performing these activities in a relational way due to two major reasons. First, participants explained they liked being treated as capable persons and felt less limited. Furthermore, they could prove to themselves they were worth something. Second, they appreciated the social contacts with their informal caregivers within the context of the help provided. During the care activity they talked and spent time with each other. One participant explained how she went to the store to buy new clothes with her informal caregiver saying: 'I needed a new dress. My daughter asked me "shall I go with you"? We visited the stores in the shopping mall. I was the happiest woman'. When the interviewer asked the participant why she was so happy, the participant answered: 'She was with me, she talked with me' (Woman, 77 years, widowed).

Another relational aspect of mastery within *care-giving* that the participants described was their own involvement in having a say in their care and support. For example, participants told their informal caregivers what needed to be done; or were asked what was needed or how things needed to be done. However, participants sometimes reported having no mastery within care-giving because informal caregivers refused the older person's participation within the informal and/or formal care settings. Participants did not like being excluded but accepted the situation as they felt powerless to change the situation. Furthermore, some participants said they understand the reason why they were not being involved.

One older woman explained that she would slow down her son and would take too much of his time saying:

He [son] goes to the store, I am not going with him. He takes his morning and goes to work at 12 p.m. I can never join him because he makes my purchases as fast as possible. I am too slow. He prefers that I do not join him, I know that (Woman, 91 years, widowed).

Participants often also received professional help. In some care settings, both formal and informal caregivers were needed. Informal caregivers helped formal care providers to gain older adults' trust or they helped the participants to access the formal care services. Furthermore, formal care providers reported to the informal caregivers if something was out of the ordinary. Some participants explained how they experienced the lack of mastery within the care setting when formal care providers discussed the care situation with the informal caregivers without involving them. According to one participant: 'Sometimes he [general practitioner] calls my daughter [and says] "Madam, I am here with your mother. There is not much progress with that medication. I suggest doing a scan". And then I receive a date' (Woman, 80 years, widowed).

3.4. Care-receiving: responsiveness

Participants described relational aspects of mastery within this element as the involvement of informal caregivers with regard to the care and support received. On the one hand, informal caregivers asked if the care and support met participants' needs; on the other hand, older participants told their informal caregivers when they were not satisfied. The latter could be about both informal and formal care received.

One older woman explained how she told her informal caregiver she was not happy to go every Sunday to his place for lunch and said:

I felt quite hurt last time. And I stopped talking. And then M. [son] asked me afterwards, "did you not feel well mama"? I said you do not understand me anymore. And I regret this a lot. He asked, "is that the reason why you are like this"? I said yes, when I speak very little, it means that I am downhearted. He will understand now (Woman, 84 years, widow).

An important aspect within this mastery as a relational activity for participants was reciprocity. Participants explained how they tried to do something back for their informal caregivers.

Some participants explained how the informal care did not met their needs. Participants explained how their informal caregivers were limited in providing care and support due to lack of time, their jobs, household, etc. Informal caregivers could also be frail themselves and therefore not able to support the older care recipients adequately. One older woman explained how she could not visit her son anymore due to her son's physical problems: 'Five years ago, I still could go to my son's home but now I cannot go anymore. He had to come get me, but he cannot do this anymore. He has back problems' (Woman, 81 years, widow).

Some participants explained how they were informal caregivers themselves. Due to their role, they could not do what they wanted and needed to take into account the care situation of the person for whom they were responsible. Said one participant: 'The service centre I was talking about. We register regularly for participating in activities. But it happens regularly that I need to call [and say] we cannot come'. When the interviewer asked why that was, the participant answered:

Because of her sickness. Now she's [spouse] good but there have been periods where I needed to get her out of the sofa, carry her to the toilet, back to the sofa. She could hardly move. You can't go to a dinner like this (Man, 81 years, married).

4. Discussion

This study reports qualitative findings on how frail, older care recipients (60+) experience relational aspects of mastery and the role of their informal caregivers in maintaining these aspects of mastery within the context of four elements of care: *caring about*, *taking care of*, *care-giving*, and *care-receiving* (Tronto, 1993). A secondary analysis of 65 semi-structured interviews with frail, community-dwelling older adults who receive care from informal caregivers was conducted using thematic (content) techniques, including both deductive and inductive coding (Cho & Lee, 2014; Fereday & Muir-Cochrane, 2006; McGraw et al., 2017).

4.1. How do frail, older adults experience relational aspects of mastery, throughout the four elements of care?

Regarding the first research question - *how do frail, older adults experience relational aspects of mastery, throughout the four elements of care?* - the results reveal that frail, older adults often describe mastery as a relational activity with their informal caregivers in one or more elements of care (Tronto, 1993). Participating within the care process and experiencing relational aspects of mastery was often defined as a valuable activity as they felt less restricted and more in control of their daily lives. This is in line with the findings of Fjordside and Morville (2016) which suggest that involving and encouraging older persons to participate in their care situation reinforces the feeling of gaining a sense of control. Older adults feel positively about help when retaining control through choice and involvement (José et al., 2016). In addition, when participants in this study were not involved in the care situation, they did not always agree with the contributions of their informal caregivers as the informal caregivers misunderstood the care needs and intervened in the wrong way. This often led to care and support which were not appropriate to the needs and wishes of older adults. This is in line with previous research findings on the importance of involving older adults in their own care and support, as levels of autonomy influence perceived experiences of health care (Gregory *et al.* 2017). Nevertheless, some participants did not want to be involved and relied completely on their informal caregivers. This is in line with several studies which indicate that not all older adults wish to have an active role in their care and support (Sak, Rothenfluh, & Schulz, 2017; Tambuyzer, Pieters, & Van Audenhove, 2014). Building a trusting relationship and receiving information are for some persons more important than actively participating in the care process (Gregory et al., 2017). In light of community care, older adults' preferences need to be properly assessed in order to offer appropriate care and support (Chiu, Feuz, McHanan, Miao, & Sudore, 2016; Kogan et al., 2015). In order to do so, frail, older adults should be supported in their autonomy.

4.2. How do frail, older adults experience the role of their informal caregivers in maintaining relational aspects of mastery over the four elements of care?

For the second research question - *How do frail, older adults experience the role of their informal caregivers in maintaining relational aspects of mastery over the four elements of care?* - the results indicate that informal caregivers are key figures in stimulating and contributing to the preservation of older adults' mastery in the various elements of care (Tronto, 1993). According to the participants, informal caregivers played a key role as counsellor within the *caring about* element of care. Older participants explained how they became attentive to their care needs as their informal caregivers noticed the care situation, discussed care needs, or gave advice. Within the *taking care of* element of care, participants explained how informal caregivers acted as co-organisers since the decision and organisation of care and support often took place in interaction with informal caregivers. Additionally, informal caregivers also took responsibility by offering help. According to Barrett et al. (2014) informal caregivers take on greater decision responsibility and often play a role in persuading the persons they care for in issues related to their care or health (e.g. to visit the doctor, to accept formal help, etc.). Regarding the *care-giving* element of care, participants explained how informal caregivers acted as good carers by involving them in their own care, doing tasks together, and letting them have a say in their care and support. Finally, within the *care-receiving* element of care, participants explained how they interacted with their informal caregivers with regard to the usefulness and value of the help received. Furthermore, care relationships need to allow reciprocity as participants valued the opportunity to do something for the persons who cared for them (Allen & Wiles, 2014; Janssen et al., 2012). Informal caregivers and care recipients have a particular relationship. Unlike other relationships, this relationship is characterised by a control-dependency imbalance (Barrett et al., 2014; Ejem, Bauldry, Bakitas, & Drentea, 2018). Recipients of care may try to reduce the difference in power with their informal caregivers by exchanging physical (e.g. help with chores), social (e.g. providing helpful company) or psychological (e.g. making the caregiver feel useful) goods (Ejem et al., 2018).

These results reveal that care is more than a unidirectional activity in which an active caregiver supports a passive and dependent person (Fine & Glendinning, 2005; Herron & Rosenberg, 2017). Care is the result of a relationship between two or more persons where all parties need to be involved (Holroyd-Leduc et al., 2016; Lloyd, Calnan, Cameron, Seymour, & Smith, 2014). When creating a basis for care, there is a need to move towards a relationship-centred care where interrelationships between caregivers and care recipients, and the importance of interpersonal interactions are taken into account (Bunn et al., 2018; Dewar & Nolan, 2013; Fjordside & Morville, 2016). Having respectful and attentive carers is one aspect of good care; namely, carers who respect the preferences and wishes of older adults, treat them as capable persons, and support and simulate them to make their own choices (José et al., 2016).

Relational aspects of mastery reflect the complexity, which is inherent in relationships between care recipients and informal caregivers. The complex role of informal caregivers in the care and support of frail, older adults is also demonstrated in a systematic review of Gillespie, Mullan and Harrison (2014) concerning medication management. In the present study, older adults experienced in addition to positive aspects of informal caregivers' role in the preservation of their mastery, also barriers that hampered the support of mastery in the four elements of care. These barriers led to unmet and unaddressed care needs. First, informal caregivers often did not have enough time to take care of their loved ones as they had additional roles besides being an informal caregiver. They often had regular jobs, their own household, etc. According to role theory (Biddle, 1986), fulfilling too many roles may have negative consequences such as role overload and role conflict. Second, informal caregivers were sometimes frail themselves. Several studies focussing on caregiving dyads indicate that informal caregivers carry a great burden, and deterioration in older care receivers' health and wellbeing has implications for the health and wellbeing of their informal caregivers (Mello et al., 2017; Oldenkamp, Hagedoorn, Wittek, Stolk, & Smidt, 2017; Ringer et al., 2016; Verbakel, Metzelthin, & Kempen, 2016). Therefore, professionals should recognise the needs of informal caregivers, engage them as proactive partners in the care process, and focus on their wellbeing as well (Adelman et al., 2014; Oldenkamp et al., 2017). As Sims-Gould and Martin-Matthews (2010) indicate, policies designed to support informal caregivers are tied to home care policy and should be implemented together. Finally, participants reported a lack of involvement when formal caregivers were present. Older adults in this study often received both informal and formal care for a wide range of care tasks. This care setting was often more complex than a dyadic relationship between the care recipients and the informal caregivers (Broese van Groenou, Jacobs, Zwart-Olde, & Deeg, 2016; Jacobs, Broese van Groenou, Aartsen, & Deeg, 2018). Older adults experienced being left out when informal caregivers had contacts with the professionals.

4.3. Strengths and limitations of the study

This study contains some limitations. First, this study performed a secondary analysis. The interviews were conducted to answer a broader range of research questions related to care and frailty in later life (Johnston, 2014). Due to this, the original data was not collected to answer the present research questions. In order to overcome this limitation, the investigators explored how well the data corresponded with the research questions by assessing the quality of the data through pre-analyses and discussion (Hox & Boeije, 2005; Johnston, 2014). Also, the investigators were very well informed and closely associated with the data collection process given their involvement in the overall study (Johnston, 2014). Second, although people with the diagnosis of dementia were excluded in the study, it cannot be stated that none of the participants had cognitive impairment. Namely most of the participants in this study were cognitively frail (i.e. presence of subjective cognitive complaints) which may indicate the presence of cognitive impairment (although not officially diagnosed by a geriatrician). This could bias the aforementioned results. However, cognitively frail participants were able to self-report their experiences on the matter. Third, despite the fact that the older participants in the study received mixed care from both informal and formal caregivers, this study focused on relational aspects of mastery and informal caregivers' role in helping frail, older adults maintain these aspects of mastery. Future research needs to consider the views of frail, older adults concerning the role and challenges of formal caregivers in the preservation of their mastery, as well as the views of formal and informal caregivers themselves. Finally, this study did not conduct dyadic interviews with informal caregivers. Studies involving the voices of caregivers' point towards the existing differences in the various actor's perceptions (Brimblecombe, Pickard, King, & Knapp, 2017; Turcotte et al., 2015) and indicate that caregivers' and care recipients' rating of control over their daily life are mutually interdependent (Rand, Forder, & Malley, 2017). Another study explored dyadic associations of mastery beliefs among older partners and suggested that partners' mastery beliefs matter for the health (behaviours) of older adults (Drewelies et al., 2018). Future research could investigate these dyadic experiences of relational aspects of mastery between care recipient and caregiver.

Despite these limitations, this study has a number of strengths. First, unlike other (quantitative) studies focusing on mastery in frail, older adults (Ezeamama et al., 2016; Lee et al., 2016; Nicolaisen et al., 2017), the qualitative design of this study allowed researchers to gain insights into the life experiences, opinions and motivations of older adults. Furthermore, this research focused on the relational dimension of mastery, defined as the ability to remain in control over one's life with help of others (Janssen et al., 2012; Verkerk, 2001). Second, in order to ensure the trustworthiness of the findings, the co-authors of this study engaged with other researchers to reduce research bias by presenting and discussing preliminary results of the study (Noble & Smith, 2015). In order to enhance the credibility of the findings, the themes were subject of discussion with the team members, and several extracts from various interviews are provided to illustrate the findings (Noble & Smith, 2015).

5. Conclusion

In the context of community care, frail, older adults in need of care and support are increasingly expected to access their social networks for help; stimulating their mastery is seen as an important way for them to do so. This study provides information on how frail, older care recipients experience relational aspects of mastery and the role of informal caregivers in maintaining these aspects of mastery over the care process. This study provides evidence that Tronto's care process provide a useful framework within which to understand how frail, community-dwelling older adults experience mastery as a relational activity with their informal caregivers. Informal caregivers also stimulate and contribute in several ways to the preservation of older adults' mastery in the different elements of care. However, several barriers to mastery as a relational activity exist and older adults, in some cases, experience a lack of involvement. Care and support should be relationship-centred where meaningful contacts between care recipients and caregivers take place, and where the preferences of older adults are assessed. Care and support must be co-produced and delivered in an equal and reciprocal relationship where information, decision-making, and help are shared among all actors. Furthermore, informal caregivers also need to be supported in order to create appropriate care and support.

References

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lach, M. S. (2014). Caregiver burden: A clinical review. *JAMA*, *311*(10), 1052-1060. doi: 10.1001/jama.2014.304

Allen, R. E. S., & Wiles, J. L. (2014). Receiving support when older: What makes it OK? *The Gerontologist*, *54*(4), 670-682. doi: 10.1093/geront/gnt047.unid

Barrett, P., Hale, B., & Butler, M. (2014). *Family care and social capital: Transitions in informal care*. Dordrecht: Springer Science + Business Media.

Biddle, B. J. (1986). Recent Developments in Role Theory. *Annual Review of Sociology*, 12, 67-92. doi: 10.1146/annurev.so.12.080186.000435

Boeije, H. (2010). *Analysis in qualitative research*. London: Sage Publications Ltd.

Brimblecombe, N., Pickard, L., King, D., & Knapp, M. (2017). Perceptions of unmet needs for community social care services in England. A comparison of working carers and the people they care for. *Health and Social Care in the Community*, *25*(2), 435-446. doi: 10.1111/hsc.12323

Broese van Groenou, M., Jacobs, M., Zwart-Olde, I., & Deeg, D. J. H. (2016). Mixed care networks of community-dwelling older adults with physical health impairments in the Netherlands. *Health and Social Care in the Community*, *24*(1), 95-104. doi: 10.1111/hsc.12199

Bunn, F., Goodman, C., Russell, B., Wilson, P., Manthorpe, J., Rait, G., et al. (2018). Supporting shared decision making for older people with multiple health and social care needs: A realist synthesis. *BMC Geriatrics*, *18*, 165-180. doi: 10.1186/s12877-018-083-9

Campbell, J., Ikegami, N., Gori, C., Barbabella, F., Chomik, R., d'Amico, F., et al. (2016). How different countries allocate long-term care resources to older users: A comparative snapshot. In C. Gori, J.-F. Fernandez & R. Wittenberg (Eds.), *Long-term care reforms in OECD countries* (pp. 47-76). Chicago: Policy Press.

Chiu, C., Feuz, M. A., McMahan, R. D., Miao, Y., & Sudore, R. L. (2016). ''Doctor, make my decisions'': Decision control preferences, advance care planning, and satisfaction with communication among diverse older adults. *Journal of Pain and Symptom Management*, *51*(1), 33-40. doi: 10.1016/j.jpainsymman.2015.07.018

Cho, J. Y., & Lee, E.-H. (2014). Reducing confusion about Grounded Theory and Qualitative Content Analysis: Similarities and differences. *The Qualitative Report*, *19*(32), 1-20.

Claassens, L., Terwee, C. B., Deeg, D. J. H., Broese van Groenou, M. I., Widdershoven, G. A. M., & Huisman, M. (2016). Development and validation of a questionnaire assessing the perceived control in health care among older adults with care needs in the Netherlands. *Quality of Life Research*, *25*, 859-870. doi: 10.1007/s11136-015-1124-2

Clancy, A., & Mahler, M. (2016). Nursing staffs' attentiveness to older adults falling in residential care – An interview study. *Journal of Clinical Nursing*, *25*(9-10), 1405-1415. doi: 10.111/jocn.13240

De Roeck, E. E., Dury, S., De Witte, N., De Donder, L., Bjerke, M., De Deyn, P. P., et al. (2018). CFAI-Plus: Adding cognitive frailty as a new domain to the Comprehensive Frailty Assessment Instrument. *International Journal of Geriatric Psychiatry*, *33*(7), 941-947. doi: 10.1002/gps.4875

José, J.d.S., Barros, R., Samitca, S., & Teixeira, A. (2016). Older persons' experiences and perspectives of receiving social care: A systematic review of the qualitative literature. *Health and Social Care in the Community*, *24*(1), 1-11. doi: 10.1111/hsc.12186

Dewar, B., & Nolan, M. (2013). Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies*, *50*(9), 1247-1258. doi: 10.1016/j.ijnurstu.2013.01.008

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Verté, D., et al. (2013a). Validation of The Comprehensive Frailty Assessment Instrument against the Tilburg Frailty Indicator. *European Geriatric Medicine*, *4*(4), 248-254. doi: 10.1016/j.eurger.2013.03.001

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Schols, J., et al. (2013b). The Comprehensive Frailty Assessment Instrument: Development, validity and reliability. *Geriatric Nursing*, *34*(4), 274-281. doi: 10.1016/j.gerinurse.2013.03.002

Dury, S. (2018). Dynamics in motivations and reasons to quit in a Care Bank: a qualitative study in Belgium. *European Journal in Ageing*. doi: 10.1007/s10433-017-0455-y

Dury, S., De Roeck, E., Duppen, D., Fret, B., Hoeyberghs, L., Lambotte, D., et al. (2017). Identifying frailty risk profiles of home-dwelling older people: Focus on sociodemographic and socioeconomic characteristics. *Aging & Mental Health*, *21*(10), 1031-1039. doi: 10.1080/13607863.2016.1193120

Dury, S., Dierckx, E., van der Vorst, A., van der Elst, M., Fret, B., Duppen, D., et al. (2018). Detecting frail, older adults and identifying their strengths: Results of a mixed-methods study. *BMC Public Health*, *18*, 191. doi: 10.1186/s12889-018-5088-3

Drewelies, J., Chopik, W. J., Hoppmann, C. A., Smith, J., & Gerstorf, D. (2018). Linked Lives: Dyadic associations of mastery beliefs with health (behavior) and health (behavior) change among older partners. *Journal of Gerontology: Series B*, *73*(5), 787-798. doi: 10.1093/geronb/gbw058

Ejem, D., Bauldry, S., Bakitas, M., & Drentea, P. (2018). Caregiver burden, care recipient depressive symptomology and social exchange: Does Race Matter? *Journal of Palliative Care*, *33*(2), 100-108. doi: 10.1177/0825859718758120

Ezeamama, A. E., Elkins, J., Simpson, C., Smith, S. L., Allegra, J. C., & Miles, T. P. (2016). Indicators of resilience and healthcare outcomes: Findings from the 2010 health and retirement survey. *Quality of Life Research*, *25*(4), 1007-1015. doi: 10.1007/s11136-015-1144-y

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, *5*(1), 80-92. doi: 10.1177/160940690600500107.

Fjordside, S., & Morville, A. (2016). Factors influencing older people's experiences of participation in autonomous decisions concerning their daily care in their own homes: A review of literature. *International Journal of Older People Nursing*, *11*(4), 284-297. doi: 10.1111/opn.12116

Fine, M., & Glendinning, C. (2005). Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing & Society*, *25*(4), 601-621. doi: 10.1017/S0144686X05003600

Gillespie, R., Mullan, J., & Harrison, L. (2014). Managing medications: The role of informal caregivers of older adults and people living with dementia. A review of the literature. *Journal of Clinical Nursing*, *23*(23-24), 3296-3308. doi: 10.1111/jocn.12519

Gregory, A., Mackintosh, S., Kumar, S., & Grech, C. (2017). Experiences of health care for older people who need support to live at home: A systematic review of the qualitative literature. *Geriatric Nursing*, *38*(4), 315-324. doi: 10.1016/j.gerinurse.2016.12.001

Grigorovich, A. (2016). The meaning of quality of care in home care settings: older lesbian and bisexual women's perspectives. *Scandinavian Journal of Caring Sciences*, *30*(1), 108-116. doi: 10.1111/scs.12228

Herron, R. V., & Rosenberg, M. W. (2017). "Not there yet": Examining community support from the perspective of people with dementia and their partners in care. *Social Science & Medicine*, *173*, 81-87. doi: 10.1016/j.socscimed.2016.11.041

Holroyd-Leduc, J., Resin, J., Ashley, L., Barwich, D., Elliott, J., Huras, P., et al. (2016). Giving voice to older adults living with frailty and their family caregivers: engagement of older adults living with frailty in research, health care decision making, and in health policy. *Research Involvement and Engagement*, *2*, 23. doi: 10.1186.s40900-016-0038-7

Holstein, M. B., Parks, J. A., & Waymack, M. H. (2011). *Ethics, aging, and society*. New York: Springer Publishing Company.

Hox, J. J., & Boeije, H. R. (2005). Data collection, Primary vs. Secondary. *Encyclopedia of Social Measurement*, 1, 593-599.

Jacobs, M. T., Broese van Groenou, M. I., Aartsen, M. J., & Deeg, D. J. H. (2018). Diversity in older adults' care networks: The added value of individual beliefs and social network proximity. *Journals of Gerontology: Series B*, *73*(2), 326-336. doi: 10.1093/geronb/gbw012

Janssen, B. M., Abma, T. A., & Van Regenmortel, T. (2012). Maintaining mastery despite age related losses. The resilience narratives of two older women in need of long-term community care. *Journal of Aging Studies*, *26*(3), 343-354. doi: 10.1016/j.jaging.2012.03.003

Johnston, M. P. (2014). Secondary data analysis: A method of which time has come. *Qualitative and Quantitative Methods in Libraries*, *3*(3), 619-626.

Keyes, S. E., Webber, S. H., & Beveridge, K. (2015). Empowerment through care: Using dialogue between the social model of disability and an ethic of care to redraw boundaries of independence and partnership between disabled people and services. *ALTER, European Journal of Disability Research*, *9*(3), 236-248. doi: 10.1016:j.alter.2015.05.002

Kogan, A. C., Wilber, K., & Mosqueda, L. (2016). Person-centered care for older adults with chronic conditions and functional impairment: A systematic literature review. *Journal of the American Geriatrics Society*, 64(1), e1-e7. doi: 10.1111/jgs.13873

Kröger, T., & Bagnato, A. (2017). Care for older people in early twenty-first-century Europe: Dimensions and directions of change. In F. Martinelli, A. Anttonen & M. Mätke (Eds.), *Social* *services disrupted. Changes, challenges and policy implications for Europe in time of austerity* (pp. 201-218). Cheltenham: Edward Elgar Publishing Limited.

Lee, W.-J., Chen, L.-K., Peng, L.-N., Chiou, S.-T., & Chou, P. (2016). Personal mastery attenuates the adverse effect of frailty on declines in physical function of older people. A 6-year population-based cohort study. *Medicine*, *94*(34), e4661. doi: 10.1097/MD.0000000000004661

Lloyd, L., Galnan, M., Cameron, A., Seymour, J., & Smith, R. (2014). Identity in the fourth age: perseverance, adaptation and maintaining dignity. *Ageing & Society*, *34*(1), 1-19. doi: 10.1017/S0144686X12000761.

Löfqvist, C., Granbom, M., Himmelsbach, I., Iwarsson, S., Oswald, F., & Haak, M. (2013). Voices on relocation and ageing in place in very old age – A complex and ambivalent matter. *The Gerontologist*, *53*(6), 919 - 927. doi: 10.1093/geront/gnt034

McCann, S., & Evans, D. S. (2002). Informal care: The views of people receiving care. *Health and Social Care in the Community*, *10*(4), 221-228. doi: 10.1046/j.1365-2524.2002.00367.x

McGraw, S., Qian, Y., Henne, J., Jarecki, J., Hobby, K., & Yeh, W.-S. (2017). A qualitative study of perceptions of meaningful change in spinal muscular atrophy. *BMC Neurology*, *17*, 68-76. doi: 10.1186/s12883-017-0853-y

Means, R., Richards, S., & Smith, R. (2008). *Community care. Policy and practice*. New York: Palgrave Macmillan.

Mello, J. d. A., Van Durme, J. M. T., Cès, S., Spruytte, N., Van Audenhove, C., & Declercq, A. (2017). The determinants of informal caregivers' burden in the care of frail older persons: a dynamic and role-related perspective. *Aging & Mental Health*, *21*(8), 838-843. doi: 10.1080/13607863.2016.1168360

Newsom, J. T., & Schulz, R. (1998). Caregiving from the recipient's perspective: Negative reactions to being helped. *Health Psychology*, *17*(2), 171-181.

Nicolaisen, M., Moum, T., & Thorsen, K. (2017). Mastery and depressive symptoms: How does mastery influence the impact of stressors from midlife to old age? *Journal of Aging and Health*, *30*(7), 1084-1107. doi: 10.1177/0898264317705782.

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-Based Nursing*, *18*(2), 34-35. doi: 10.1136/eb-2015-102054.

Oldenkamp, M., Hagedoorn, M., Wittek, R., Stolk, R., & Smidt, N. (2017). The impact of older person's frailty on the care-related quality of life of their informal caregiver over time:

Results from the TOPICS-MDS project. *Quality of Life Research*, *26*(10), 2705-2716. doi: 10.1007/s11136-017-1606-5

Oliveira, M., Bitencourt, C., Teixeira, E., & Santos, A. C. (2013). Thematic content analysis: Is there a difference between the support provided by the MAXQDA® and NVivo® software packages. In A. Mesquita & I. Ramos (Eds.), *Proceedings of the 12th European Conference on Research Methodology for Business and Management Studies* (pp. 304-314). Guimaraes, Portugal: University of Minho.

Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior*, *19*(1), 2-21. doi: 10.2307/2136319

Perkins, M. M., Ball, M. M., Whittington, F. J., & Hollingsworth, C. (2012). Relational Autonomy in Assisted Living: A Focus on Diverse Care Settings for Older Adults. *Journal of Aging Studies*, 26(2), 214-225. doi: 10.1016/j.jaging.2012.01.001

Rand, S., Forder, J., & Malley, J. (2017). A study of dyadic interdependence of control, social participation and occupation of adults who use long-term care services and their carers. *Quality of Life Research*, *26*(12), 3307-3321. doi: 10.1007/s11136-017-1669-3

Ringer, T. J., Hazzan, A. A., Kennedy, C. C., Karampatos, S., Patterson, C., Marr, S., et al. (2016). Care recipients' physical frailty is independently associated with subjective burden in informal caregivers in the community setting: A cross-sectional study. *BMC Geriatrics*, *16*, 186. doi: 10.1186/s12877-016-0355-6

Sak, G., Rothenfluh, F., & Schulz, P. J. (2017). Assessing the predictive power of psychological empowerment and health literacy for older patients' participation in health care: A cross-sectional population-based study. *BMC Geriatrics*, *17*, 59. doi: 10.1186/s12877-017-0448-x

Sims-Gould, J., & Martin-Matthews, A. (2010). We share the care: Family caregivers' experiences of their older relative receiving home support services. *Health and Social Care in the Community*, *18*(4), 415-423. doi: 10.1111/j.1365-2524.2010.00913.x

Stones, D., & Gullifer, J. (2016). 'At home it's just so much easier to be yourself': Older adults' perceptions of ageing in place. *Ageing & Society*, *36*(3), 449-481. doi: 10.1017/So144686X14001214

Tambuyzer, E., Pieters, G., & Van Audenhove, C. (2014). Patient involvement in mental health care: One size does not fit all. *Health Expectations*, *17*(1), 138-150. doi: 10.1111/j.1369-7625.2011.00743.x

Turcotte, P.-L., Larivière, N., Desrosiers, J., Voyer, P., Champoux, N., Carbonneau, H., et al. (2015). Participation needs of older adults having disabilities and receiving home care: Met needs mainly concern daily activities, while unmet needs mostly involve social activities. *BMC Geriatrics*, *15*, 95. doi: 10.1186/s12877-015-0077-1

Tronto, J. C. (1993). *Moral Boundaries. A Political Argument for an Ethic of Care*. New York: Routledge.

Vandeurzen, J. (2016). *Nabije zorg in een warm Vlaanderen. Vlaams Mantelzorgplan 2016-2020*. Retrieved on 21 March 2018, from http://www.jovandeurzen.be/sites/jvandeurzen/files/Vlaams%20Mantelzorgplan_0.pdf

Verbakel, E., Metzelthin, S. F., & Kempen, G. I. J. M. (2016). Caregiving to older adults: Determinants of informal caregivers' subjective well-being and formal and informal support as alleviating conditions. *Journals of Gerontology: Series B*, *73*(6), 1099-1111. doi: 10.1093/geronb/gbw047

Verkerk, M. A. (2001). The care perspective and autonomy. *Medicine, Health Care and Philosophy*, *4*(3), 289-294. doi: 10.1023/A:1012048907443

Willemse, E., Anthierens, S., Farfan-Portet, M. I., Schmitz, O., Macq, J, Bastiaens, H., et al. (2016). Do informal caregivers for elderly in the community use support measures? *BMC Health Services Research*, *16*, 270-279. doi: 10.1186/s12913-016-1487-2

Chapter 6. Frailty differences in older adults' use of informal and formal care

Manuscript published

Lambotte, D., De Donder, L., Van Regenmortel, S. Fret, B., Dury, S., Smetcoren, A.-S., Dierckx, E., De Witte, N., Verté, D., & the D-SCOPE Consortium. (2018). Frailty differences in older adults' use of informal and formal care. *Archives of Gerontology and Geriatrics*, *79*, 69-77. doi: 10.1016/j.archger.2018.05.018

Abstract

Objectives: This study examines different combinations of informal and formal care use of older adults and investigates whether these combinations differ in terms of need for care (physical and psychological frailty) and enabling factors for informal and formal care use (social and environmental frailty).

Methods: Using cross-sectional data from the Belgian Ageing Studies (survey, N = 38,066 community-dwelling older adults), Latent Class Analysis (LCA) is used to identify combinations of informal and formal care use. Bivariate analyses are used to explore the relationship between the different combinations of care use and frailty.

Results: Latent Class Analysis (LCA) identified 8 different types of care use, which vary in combinations of informal and formal caregivers. Older adults who are more likely to combine care from family and care from all types of formal caregivers are more physically, psychologically and environmentally frail than expected. Older adults who are more likely to receive care only from nuclear family, or only from formal caregivers are more socially frail than expected.

Conclusions: Older adults with a higher need for care are more likely to receive care from different types of informal and formal caregivers. High environmental frailty and low social frailty are related with the use of care from different types of informal and formal caregivers. This study confirms that informal care can act as substitute for formal care. However, this substitute relationship becomes a complementary relationship in frail, older adults. Policymakers should take into account that frailty in older adults affects the use of informal and formal care.

Keywords

Informal and formal care; community-dwelling older adults; frailty; Latent Class Analysis; variety in informal and formal care use; substitution vs. complementarity

1. Introduction

As adults become frail and older dependent for care and support, the demand for both informal and formal care within an ageing society will keep growing (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011; Jacobs, Van Tilburg, Groenewegen, & Broese van Groenou, 2016). In response to the challenges of an ageing society governments in different countries are introducing a care model named community care (Aggar, Ronaldson, & Cameron, 2011; Carpenter et al., 2004; Genet et al., 2011). Within this care model formal care is being provided within the community of an individual (as opposed to institutionalisation) and in addition volunteers and informal caregivers are considered as im- portant actors for ensuring care and support to (frail) older adults (Barrett, Hale, & Butler, 2014). Most older adults prefer to age in place and stay in their own home and community as long as possible, even when they become frail and in need of care and support (Wiles, Leibing, Guberman, Reeve, & Allen, 2011). In Europe, policymakers in several countries are encouraging informal care as an alternative for more ex- pensive formal care (Bonsang, 2009; Van den Berg, Brouwer, & Koopmanschap, 2004). However, the number of (potential) informal caregivers will diminish over the years due to societal trends like declining family size, changing living arrangements, increasing participation of women in the labour market, etc. (Colombo et al., 2011; Ryan, Smith, Antonucci, & Jackson, 2012). One of the challenges of com- munity care raises the question on how informal and formal caregivers can meet the demand for home care to older adults (Colombo et al., 2011). Therefore, this article aims to provide more insights about the combinations of informal and formal care use of (frail) older adults.

A considerable amount of studies has been published on the use of informal and formal care by community-dwelling older adults and highlights the need to understand the relationship between both types of care (e.g. Ku, Liu, & Wen, 2013; Litwin & Attias-Donfut, 2009; Paraponaris, Davin, & Verger, 2012). First, these studies demonstrate that informal care is a major source of care and support to older adults (Paraponaris et al., 2012; Rodriguez, 2014; Van den Berg et al., 2004). Second, informal care is not only the most frequently provided care to older adults it is also often preferred above formal care by older adults themselves (Eckert, Morgan, & Swamy, 2004). Third, several studies highlight the individual characteristics in the use of informal and formal care (Broese van Groenou, Glaser, Tomassini, & Jacobs, 2006; Gannon & Davin, 2010; Ku et al., 2013; Larsson & Silverstein, 2004; Sigurdardottir & Kareholt, 2014). For example, Broese van Groenou et al. (2006) suggest that being older, never married or widowed, or having a low socio-economic status increase the use of both informal and formal care in Belgium, Great Britain, Italy and the Netherlands. Finally, some studies focus on the possible combinations between in- formal and formal care and describe these relationships in terms of substitution or complement (e.g. Greene, 1983; Moscovice, Davidson, & McCaffrey, 1988; Stabile, Laporte, & Coyte, 2006; Van Houtven & Norton, 2004).

Despite the fact that older adults receive help from different types of informal caregivers (Kalwij, Pasini, & Wu, 2014) and formal care providers (Hoeck et al., 2011), to date little empirical studies consider the use of multiple informal and/or formal caregivers by older adults (e.g. Gannon & Davin, 2010; Larsson & Silverstein, 2004). The study at hand aims to fill this research gap by taking into account different types of informal and formal caregivers in the creation of more diverse combi- nations of care use by older adults.

1.1. Background

Two theoretical approaches, the substitution theory and the complementary theory, are often addressed in research regarding the use of informal and formal care by community-dwelling older adults. Greene (1983) firstly explored informal and formal care in terms of substitute or complement. He looked at whether publicly financed formal home care tended to replace informal care provided by family and friends or complement it. There were some concerns in the U.S. that new policy initiatives would not only complement informal care but also to some extent substitute informal care (United States, Health Care Financing Administration, Office of Policy Analysis, 1981). Greene (1983) concluded that the provision of formal home care services implies a re- duction or rescission of the informal care previously provided. Ensuing from this research, several other studies described the relationship between informal and formal care in terms of substitute or complement (e.g. Moscovice et al., 1988; Stabile et al., 2006; Van Houtven & Norton, 2004).

The substitute model indicates that the use of one type of care re- duces and eventually replaces the use of the other type of care. This can go both ways: while some studies provide evidence that formal care substitutes informal care (e.g. Stabile et al., 2006), other studies provide contrasting results and conclude that informal care substitutes formal care (e.g. Bolin, Lindgren, & Lundborg, 2008; Gannon & Davin, 2010). Like Greene (1983); Stabile et al. (2006) concluded that when the availability of publicly financed formal home care increases, older adults are more likely to use this type of care and less likely to use informal care. In contrast to these results, some studies highlight the inverse substitute relationship and suggest that informal care substitutes formal care (Bolin et al., 2008; Gannon & Davin, 2010; Hanaoka & Norton, 2008; Van Houtven & Norton, 2004). From this perspective community-dwelling older adults who receive informal care are less likely to call upon formal care providers. For example, Hanaoka and Norton (2008) concluded that older adults who receive care from their children are less likely to use formal care such as home health care.

The complementary model suggests that formal care enters into the care situation of an older person when informal care is inadequate, or when there is a substantial need for formal home care (Chappell & Blandford, 1991). In other words, the care tasks are being shared whereby formal caregivers provide care and support which informal caregivers are unable to give. Regarding the complementary model, certain studies provide evidence that formal care is more likely to be used in combination with informal care (Blomgren, Martikainen, Martelin, & Koskinen, 2008; Bolin et al., 2008; Moscovice et al., 1988; Van Houtven & Norton, 2004). For example, Moscovice et al. (1988) demonstrated that the amount of informal care is not significantly determined by the amount of formal home care services used by com- munity-dwelling older adults, suggesting that formal care is a complement rather than a substitute for informal care.

Within the relationship between informal and formal care in terms of substitute or complement, some studies provide nuanced results, depending on factors such as the type of informal or formal caregiver, or the level of disability of an older person. First, Van Houtven and Norton (2004) concluded that informal care provided by children substitutes for different types of formal care, namely home health care, nursing home care, hospital care and physician visits. However, for outpatient surgery, informal care from children acts as a complement. Bolin et al. (2008) support these research results as they indicated that informal care substitutes for formal home care except for doctor- and hospital visits where informal care acts as a complement. Second, Bonsang (2009) concluded that the level of physical disability of an older person changes the relationship between informal and formal care. Informal care is likely to act as a substitute for formal home care when an older person has a low level of disability. But as the level of disability increases, the care charge increases and requires both in- formal and formal care. At this moment, the relationship between in- formal and formal care is likely to become complementary (Bonsang, 2009).

Despite substantial work conducted to date studies have failed to consider different types of informal care, and a broader view on care needs. As Byrne, Goeree, Hiedemann and Stern (2009) state, most research merely takes into account a narrow category of informal care- givers and multiple informal care is still under-studied. Some studies for example only investigate the relationship between informal care provided by adult children and formal care in older adults (Bonsang, 2009; Hanaoka & Norton, 2008; Van Houtven & Norton, 2004). In line with research demonstrating the impact of different types of formal care providers (Hoeck et al., 2011), also several types of informal caregivers exist, such as spouse, children, friends, neighbours, etc. (Kalwij et al., 2014; Keating & Dosman, 2009). Within this perspective, a study from Keating, Otfinowski, Wenger, Fast, and Derksen, 2003 as well as more recent research (e.g. Jacobs et al., 2016; Koehly, Ashida, Schafer, & Ludden, 2015) argue to approach this matter from a network perspective and underline the importance of stepping away from a dyadic perspective for informal and formal care. A study from Kemp, Ball, and Perkins, (2013) introduces an alternative model for studying care net- works, the convoy of care, and demonstrates the complexity and dynamicity of care networks. The convoy of care model explores care relations as processes that evolve over time and uses the convoy metaphor of Kahn and Antonucci (1980) in combination with key elements from different conceptual models (e.g. life-course). In addition, previous studies have only focused on changing relationships in terms of physical disabilities (Bonsang, 2009; Kemper, 1992). Yet, older adults themselves as well as different researchers identify frailty not as a physical matter only, but as a multidimensional issue including physical, psychological, social and environmental aspects (Armstrong, Stolee, Hirdes, & Poss, 2010; Bergman et al., 2007; De Witte et al., 2013a; Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010; van Assen, Pallast, El Fakiri, & Gobbens, 2016). In this study frailty is operationalised as a multidimensional concept that considers the complex interplay of physical, psychological, social and environmental factors (Armstrong et al., 2010; De Witte et al., 2013a; De Witte et al., 2013b; Markle-Reid & Brown, 2003).

1.2. Purpose of the study

This study sets out to test the hypothesis that frailty plays a role in combinations of informal and formal care use of older adults. We test if older adults receiving care from both informal and formal caregivers differ in frailty levels (physical, psychological, social, environmental). Additionally, we examine frailty levels of older adults in need of assistance receiving help from no one. Therefore, we use the model of health care services use from Andersen and Newman (2005). This model contributes to the understanding of variations in care use by providing a theoretical framework for health care services use. The model underlines the importance of (1) characteristics of the health services delivery system, (2) changes in medical technology and societal norms of health care services use and (3) individual determinants of health care services use. In particular, the individual characteristics are useful in this study as frailty is an individual condition which may contribute to the amount of care use. The model of health care services use defines three individual determinants: (1) the disposition to use care, (2) enabling factors that facilitate the use of care and (3) the need for care. Predisposing components are characteristics that make someone liable to use care, for example demographic characteristics (e.g. age), social characteristics (e.g. education) and attitudes or beliefs. Enabling components concern the resources which must be available for individuals in order to use care, such as income or the presence of health facilities in the community. Finally, the need for care regards the perception of need or the probability of its occurrence (e.g. health impairment). With regard to frailty, physical and psychological frailty may reflect the increased need for care and support, which can cause the care network to grow. Social and environmental frailty are approached as enabling factors where social frailty may indicate a lack of social network resources and environmental frailty a lack of material resources.

In accordance with the aforementioned research gaps, two research questions are posed:

1. How does informal and formal care relate to each other in combi- nations of care use of community-dwelling older adults?
2. To what degree are older adults' need for care (physical and psychological frailty) and enabling factors (social and environmental frailty) associated with the different combinations of care use?

2. Materials and methods

2.1. Data collection and study population

The cross-sectional data for this study originate from the Belgian Ageing Studies (BAS), a research project which explores issues of quality of life among community-dwelling older adults, i.e., informal care, formal care, frailty, wellbeing, social participation, housing, etc. by using a standardised survey (see De Donder et al., 2014 for a full description). The data for the study at hand were gathered between 2008 and 2014 among 38,066 community-dwelling older adults aged 60 years and over, living in 83 municipalities in the Flemish region of Belgium and in Brussels.

The data were collected through a participatory peer-research methodology. Older adults were not only the researched group but also participated actively in the research project as volunteers in the data collection process. In particular through delivering and collecting surveys and clarifying questions to respondents if needed. In order to do so, these older volunteers received training and feedback sessions. Respondents were informed of the voluntary nature of their involvement in the research project, their right to refuse to participate and the privacy of their response. Participation was free of any remuneration.

The participating municipalities were not randomly selected but decided freely to participate in the research project. A representative sample was created in each participating municipality by selecting randomly community-dwelling older adults from the census records, stratified by age (60–69; 70–79; 80+) and gender. The sampling fraction depended on the size of the municipality, varying between N = 109 and N = 984. In order to reduce the potential bias of non- response, two additional samples were selected in the same quota category as an alternate for respondents who refused to participate or were not able to fill in the questionnaire.

The original database consisted of 38,066 community-dwelling older adults (60+). Community-dwelling older adults in need of assistance who received care or support were included in this study, as well as older adults in need of assistance who received help from no one. This reduced the dataset to N = 12,481. This final sample consisted of 35.7% men and 64.3% women. 27.1% older adults were aged between 60 and 69 years, 36.3% between 70 and 79 years and 36.7% were aged 80 years and over. Regarding marital status 56.4% older adults were married, 33.5% widowed, 4.5% never married, 4.1% divorced and 1.6% cohabiting. 37.5% older adults only finished primary education. Finally, 21.0% older adults had a monthly household income less than € 1000, 40.5% between € 1000 and € 1499, 18.8% between € 1500 and € 1999 and 19.7% more than € 1999.

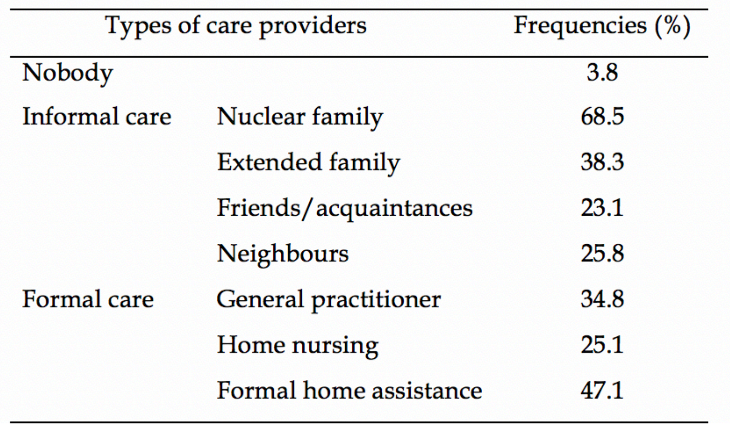
2.2. Measurements

Informal and formal care use

Respondents who indicated to be in need of assistance for personal care, housekeeping and/or personal mobility were asked from who they received assistance. For this question, 16 possibilities were mentioned: the first possibility was 'nobody', followed by 15 possible care providers (persons or organisations). Respondents who indicated at least one of these 15 possible care providers were labelled as care recipient. From this, different items were integrated in 7 categories of care use. 4 of the 7 categories referred to informal care: (1) nuclear family (partner and/ or children); (2) extended family (grandchildren and/or other relatives); (3) friends and acquaintances; and (4) neighbours. The other 3 categories referred to formal care: (1) general practitioner; (2) home nursing; and (3) formal home assistance (senior companion care, services for home care, cleaning services, grocery services, chores services, hot meals and/or day care/short term care). Respondents in need of assistance for personal care, housekeeping and/or personal mobility who indicated receiving assistance from no one were also included in this study (N = 477).

Table 6 provides the descriptive statistics for the care variables.

Table 6. Descriptive statistics of older adults in need of assistance who receive care from no one, informal caregivers and formal care providers (N = 12,481)



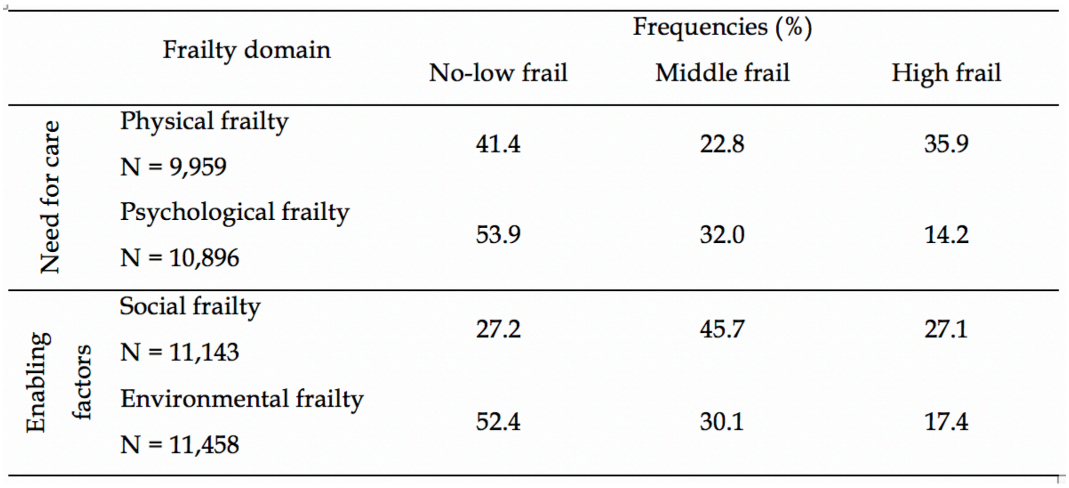
Types of care providers		Frequencies (%)
Nobody		3.8
Informal care	Nuclear family	68.5
	Extended family	38.3
	Friends/acquaintances	23.1
	Neighbours	25.8
Formal care	General practitioner	34.8
	Home nursing	25.1
	Formal home assistance	47.1

Need for care (physical and psychological frailty) and enabling factors (social and environmental frailty)

Frailty in older adults was measured using the Comprehensive Frailty Assessment Instrument (CFAI) (De Witte et al., 2013a). The CFAI is a self-assessment instrument that measures 4 domains of frailty in older adults, namely physical, psychological, social and environmental frailty. The physical domain assesses the general physical health with 4 items (e.g. walking up a hill or stairs); the psychological domain evaluates mood-disorders (e.g. feeling unhappy) and emotional loneliness (e.g. I miss having people around me) with 8 items; the social domain contains social loneliness (e.g. there are enough people I feel close to) and social support (e.g. social support network 1) with 6 items; and the environmental domain captures conditions of inadequate housing with 5 items (e.g. my house is in a bad condition). The CFAI was validated among 33,629 older adults, using a second-order confirmatory factor analysis (De Witte et al., 2013a). The CFAI was internally consistent (Cronbach's α = 0.812), explaining 63.6% of the variance in frailty and had good model fit indices: Root Mean Square Error of Approximation (RMSEA) = 0.032 (90% interval = 0.032 to 0.033); Comparative Fit Index (CFI) = 0.974; Tucker- Lewis Index (TLI) = 0.970. Using a two-step cluster analysis each frailty domain was recoded into 3 classes: no-low frail; mild frail; and high frail.

Table 7 provides the descriptive statistics for the frailty indicators.

Table 7. Descriptive statistics of frailty as need for care (physical and psychological frailty) and as enabling factors (social and environmental frailty) among older adults in need of assistance



	Frailty domain	Frequencies (%)		
		No-low frail	Middle frail	High frail
Need for care	Physical frailty N = 9,959	41.4	22.8	35.9
	Psychological frailty N = 10,896	53.9	32.0	14.2
Enabling factors	Social frailty N = 11,143	27.2	45.7	27.1
	Environmental frailty N = 11,458	52.4	30.1	17.4

2.3. Data analysis

Latent Class Analysis

To identify combinations of informal and formal care use among community-dwelling older adults, a Latent Class Analysis (LCA) was performed. This technique is used for analysing relationships in categorical data and enables the characterisation of latent (unobserved) variables through analysing the structure of the relationships among several manifest (observed) variables (McCutcheon, 1987). In this study, LCA enhanced the conceptualisation of patterns of care use by categorising groups of older care recipients based on similarities in their informal and formal care use. Therefore, we used the software program

LEM (Vermunt, 1997). To determine an optimal exploratory latent class model, we started computing a latent class model with only one single latent class and increased the number of classes, while checking for model fit. The goodness of fit was assessed using the Akaike's Information Criterion (AIC) and Bayesian Information Criterion (BIC) of L-square (e.g. Van Der Ark & Richards, 2006). The lower the AIC and BIC, the better the model fits (Nylund, Asparouhov, & Muthèn, 2007). However, to avoid creating too many classes of care use and enhance manageability and interpretability, we accepted the model where both AIC and BIC showed negative values. To detect boundary estimates, avoid local optima and ensure that non-identified parameter estimates did not affect the values of the latent class probabilities, the chosen model was conducted 20 times using different starting values (e.g. Van Der Ark & Richards, 2006). We considered the best solution out of 20 as the global optimum. In order to perform statistical analyses with the LCA model in SPSS, we created a single latent variable with a set of underlying classes by modal assignment. We recognise that the use of modal assignment leads to a certain amount of misclassification errors (McCutcheon, 1987). As a consequence, relative frequencies of the different classes do not exactly reproduce the class sizes as estimated by LEM. We therefore report 2 sets of parameters, the relative size class of the sample as given in SPSS and the conditional probability derived from the LCA analysis in LEM. The LCA model was considered as a nominal outcome in the final analytic model.

Bivariate analyses

We analysed the data using the Statistical Package for the Social Sciences (SPSS), version 23, IBM. Chi-square correlations were per- formed to explore the relationship between the different domains of frailty and the classes of care use, estimated by LCA. Additionally, we used standardised residuals to measure the strength of the difference between observed and expected counts and to investigate which cells are contributing the most to the chi-square value (Agresti, 2007). Standardised residuals greater than 2 within the high frail group are discussed. For the chi-square analyses, we created an additional class in SPSS for the older adults who reported to be in need of assistance, but who indicated to receive assistance from no one.

Due to the large dataset significance was reached when $p \leq 0.001$ (Field, 2009).

3. Results

3.1. Combinations of informal and formal care use of community-dwelling older adults

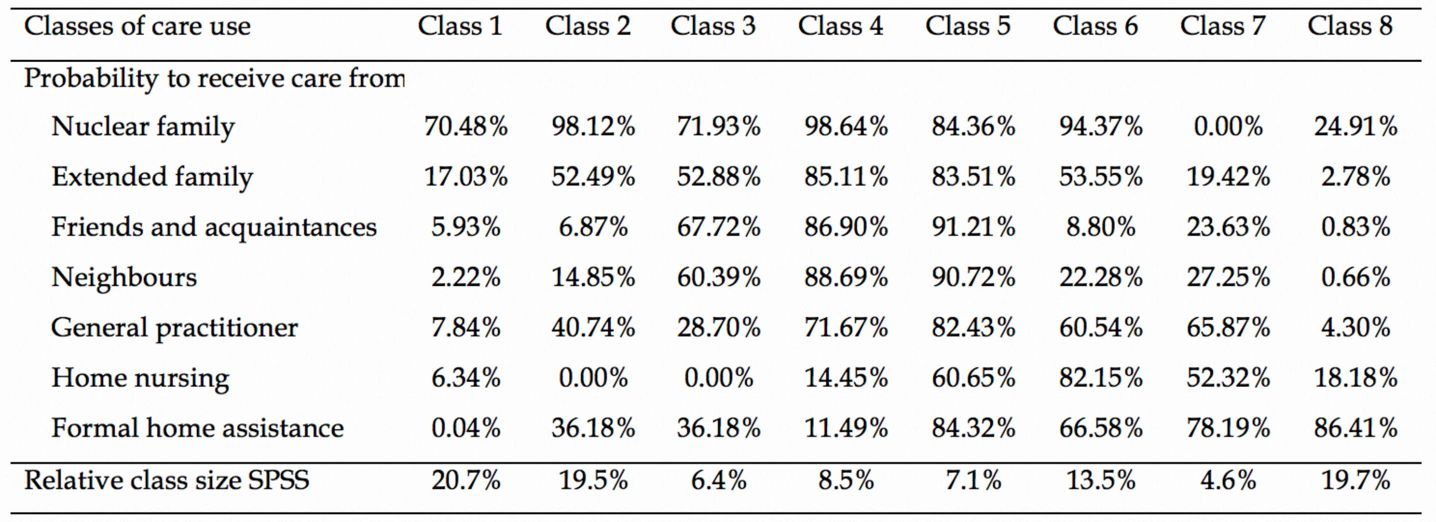
Table 8 reports the results of the Latent Class Analysis. When both the AIC and BIC showed negative values, LCA reported 8 different combinations of care use among community-dwelling older adults (AIC = −2.8781, BIC = −477.2497).

First, 3 classes of care use were characterised by older adults in need of assistance who were more likely to receive care solely from informal caregivers (46.6% of the sample size). Class 1 represented 20.7% of the sample and consisted of older adults who were more likely to receive care only from nuclear family caregivers, i.e. care from spouse and/or children. Class 2 (19.5% of the sample) identified older adults who were more likely to receive care both from nuclear and extended family caregivers, i.e. care from spouse, children, grandchildren and/or other relatives. Class 3 (6.4% of the sample) comprised older adults who were more likely to receive care from all types of informal caregivers, i.e. nuclear and extended family caregivers, friends and acquaintances, and neighbours.

Second, 3 classes of care use were characterised by older adults in need of assistance who were more likely to receive care from both in- formal caregivers and formal caregivers (29.1% of the sample size). Class 4 (8.5% of the sample) identified older adults who were more likely to receive care from all types of informal caregivers in combination with care from the general practitioner. Older adults in class 5 (7.1% of the sample) were more likely to receive care from all types of informal caregivers in combination with care from all types of formal care providers, i.e. care from the general practitioner, home nursing and formal home assistance. Class 6 represented 13.5% of the sample and consisted of older adults who were more likely to combine informal care from family (both nuclear and extended) with formal care from all types of formal care providers.

Finally, 2 classes of care use consisted of older adults in need of assistance who were more likely to receive care only from formal care providers (24.3% of the sample size). Class 7 (4.6% of the sample) comprised older adults who were more likely to receive care from all types of formal care providers. Class 8 represented 19.7% of the sample and consisted of older adults who were more likely to receive formal home assistance only.

Table 8. Combinations of informal and formal care use of community-dwelling older adults: Latent Class Analysis (N = 12,004)



Classes of care use	Class 1	Class 2	Class 3	Class 4	Class 5	Class 6	Class 7	Class 8
Probability to receive care from								
Nuclear family	70.48%	98.12%	71.93%	98.64%	84.36%	94.37%	0.00%	24.91%
Extended family	17.03%	52.49%	52.88%	85.11%	83.51%	53.55%	19.42%	2.78%
Friends and acquaintances	5.93%	6.87%	67.72%	86.90%	91.21%	8.80%	23.63%	0.83%
Neighbours	2.22%	14.85%	60.39%	88.69%	90.72%	22.28%	27.25%	0.66%
General practitioner	7.84%	40.74%	28.70%	71.67%	82.43%	60.54%	65.87%	4.30%
Home nursing	6.34%	0.00%	0.00%	14.45%	60.65%	82.15%	52.32%	18.18%
Formal home assistance	0.04%	36.18%	36.18%	11.49%	84.32%	66.58%	78.19%	86.41%
Relative class size SPSS	20.7%	19.5%	6.4%	8.5%	7.1%	13.5%	4.6%	19.7%

3.2. Older adults’ need for care (physical and psychological frailty) and enabling factors (social and environmental frailty) according to combinations of care use

Using Chi-square analyses, we compared the different combinations of care use of older adults according to their frailty levels (Table 9). For these analyses, we created an additional class including older adults in need of assistance who reported receiving assistance from no one (class 9). We found a significant difference between the domains of frailty and the different combinations of care use ($p \leq 0.001$). The standardised residuals allowed investigating which combinations were contributing the most to the Chi-square values. These results in the high frail group are described below.

Regarding physical frailty, older adults in need of assistance who were more likely to combine care from family (both nuclear and ex- tended) with care from all types of formal care providers (class 6) were more physically frail than expected. 61.6% older adults in this class were physically frail. Also, older adults in need of assistance who were more likely to receive care from all types of informal caregivers in combination with care from all types of formal care providers (class 5, 43.6%) as well as only from all types of formal care providers (class 7, 44.7%) were more physically frail than expected.

Regarding psychological frailty, older adults in need of assistance who were more likely to receive care from family (both nuclear and extended) in combination with care from all types of formal care providers (class 6, 18.9%) were more psychologically frail than expected. Also, older adults in need of assistance who were more likely to receive care only from all types of formal care providers (class 7) were more psychologically frail than expected. In this class, 22.7% older adults were psychologically frail.

When looking at social frailty, older adults in need of assistance who were more likely to receive care solely from nuclear family (class 1) were more socially frail than expected. 37.6% older adults in this class were socially frail. Also, older adults in need of assistance who were more likely to receive formal home assistance only (class 8, 40.3%) and older adults in need of assistance who were more likely to receive help from no one were more socially frail than expected (class 9, 37.0%).

Regarding environmental frailty, older adults in need of assistance who were more likely to receive care from family (both nuclear and extended) in combination with care from all types of formal care providers (class 6, 22.2%) were more environmentally frail than expected. Also, older adults in need of assistance who were more likely to receive care only from all types of formal care providers (class 7, 21.1%) had higher proportions of environmental frailty.

Table 9. Older adults' need for care (physical and psychological frailty) and enabling factors (social and environmental frailty) according to combinations of care use

	Frailty		Sample of users	Classes of care use (%)									X^2
				Class 1	Class 2	Class 3	Class 4	Class 5	Class 6	Class 7	Class 8	Class 9	
Need for care	Physical frailty (N = 9,959)	No-low frail	41.4%	51.4*	39.9	47.1*	51.8*	32.7	18.3	28.3	43.5	66.6*	754.343**
		Mild frail	22.8%	20.7	23.5	24.9	21.0	23.7	20.2	27.0	26.2*	17.6	
		High frail	35.9%	28.0	36.6	27.9	27.2	43.6*	61.6*	44.7*	30.3	15.8	
	Psychological frailty (N = 10,896)	No-low frail	53.9%	56.13	55.2	57.9	61.8*	50.6	42.5	42.7	55.7	60.4	173.998**
		Mild frail	32.0%	31.2	32.5	27.6	26.9	35.4	38.7*	34.7	29.9	29.1	
		High frail	14.2%	12.5	12.3	14.4	11.3	14.0	18.9*	22.7*	14.4	10.5	
Enabling factors	Social frailty (N = 11,143)	No-low frail	27.2%	17.2	29.6*	30.8	55.5*	48.5*	27.1	5.5	17.6	23.2	1250.886**
		Mild frail	45.7%	45.3	48.2	48.4	37.3	42.6	51.4*	57.1*	42.1	39.9	
		High frail	27.1%	37.6*	22.2	20.8	7.3	8.9	21.5	37.4*	40.3*	37.0*	
	Environmental frailty (N = 11,458)	No-low frail	52.4%	55.1	51.3	48.7	53.1	48.9	44.4	54.8	58.1*	53.5	107.245**
		Mild frail	30.1%	28.2	31.3	32.5	31.5	32.3	33.4*	24.1	28.4	27.7	
		High frail	17.4%	16.7	17.4	18.8	15.4	18.7	22.2*	21.1*	13.5	18.8	

Note. * = Standardised residuals greater than 2; ** = $p < 0.001$

4. Discussion

This study investigated the informal and formal care use by community-dwelling older adults in the Flemish region of Belgium and in Brussels. Using data from the Belgian Ageing Studies (De Donder et al., 2014), we created combinations of informal and formal care use by using Latent Class Analysis (LCA). We therefore considered different types of informal and formal caregivers. We furthermore analysed whether these combinations differ in levels of frailty. In this study frailty was not only defined as a physical problem but also as a psychological, social and environmental issue (De Witte et al., 2013a).

Based on empirical results, the first research question "how does informal and formal care relate to each other in combinations of care use of community-dwelling older adults" can be answered. LCA identified 8 different combinations of care use among community-dwelling older adults. Similar with Paraponaris et al. (2012) and Rodriguez (2014), this study shows that informal care is the most important source of care for older adults. 75.7% older adults in need of assistance were more likely to receive care from informal caregivers, with or without receiving care from formal care providers. In accordance with Bolin et al. (2008) and Van Houtven and Norton (2004), informal care in our study can be considered as a valuable substitute for formal care since almost half of the respondents (46.6%) were more likely to receive care only from informal caregivers. Nuclear family only substitutes formal care in class 1, nuclear and extended family substitute formal care in class 2, and nuclear and extended family, friends and neighbours substitute formal care in class 3. Our results also confirm that older adults rely principally on their spouse or children (Johnson & Wiener, 2006). Namely, 20.7% older adults in need of assistance in our study were more likely to receive informal care from nuclear family only. But, similar with Byrne, Goeree, Hiedemann, and Stern (2009) as well as Keating and Dosman (2009), other groups of older adults in need of assistance were more likely to receive care from multiple types of in- formal caregivers: 19.5% older adults in need of assistance were more likely to receive care from nuclear and extended family, and 6.4% from all types of informal caregivers (including friends and acquaintances and neighbours). 29.1% older adults in need of assistance were more likely to receive care from both informal and formal caregivers. The majority of these older adults (13.5%) were more likely to receive care from nuclear and extended family in combination with care from all types of formal care providers. Finally, two classes of only formal care substitute informal care (24.3%): 4.6% older adults in need of assistance were more likely to receive care from all types of formal care providers only and 19.7% only from formal home assistance, i.e. services for home care, cleaning services, grocery services, chores services, hot meals and/or day care/short term care.

These results are in accordance with recent studies indicating the existence of mixed care networks for community-dwelling older adults (e.g. Broese van Groenou, Jacobs, Zwart-Olde, & Deeg, 2016; Jacobs et al., 2016; Kemp et al., 2013). Some of these studies also used clus- tering techniques to identify care network types (e.g. Broese van Groenou et al., 2016; Jacobs, Broese van Groenou, Aartsen, & Deeg, 2018). Two issues need to be discussed concerning the use of this methodological analysis to identify care networks. First, other studies distinguished different combinations of informal and formal care use, however they either used other samples or different input variables (e.g. Broese van Groenou et al., 2016; Jacobs et al., 2018). Broese van Groenou et al. (2016) and Jacobs et al. (2018) both identified four care network types. The identification of eight classes in our study could be the result of the detailed information on types of caregivers (i.e. 15 different types of caregivers). Several classes resemble to those found in other studies, for example Jacobs et al. (2018) also identified a diverse informal care network containing friends and neighbours next to family caregivers. Other results are different, for example Broese van Groenou et al. (2016) identified a mixed care network with approximately half of the informal caregivers living with the care recipient (i.e. information about where the caregiver lived was not available in our study). Second, the studies using clustering techniques (including ours) identified only care networks including mixed care networks, although they varied in the ratio of informal and formal caregivers present. None of the classes identified used only informal or formal care. This implies that the distinction between either formal or informal or mixed care, as used in many studies, is not appropriate.

By answering the second research question (to what degree are older adults' need for care (physical and psychological frailty) and enabling factors (social and environmental frailty) associated with the different combinations of care use?), this study extents findings concerning variations of care use. Based on the model of health care services use (Andersen & Newman, 2005), frailty is defined both as a need for care (i.e. physical and psychological frailty) and as enabling factors for care (i.e. social and environmental frailty). Significant differences were found when comparing the different combinations of care use to frailty levels in community-dwelling older adults in need of assistance.

First, when frailty is approached as a need for care (Andersen & Newman, 2005), the results indicate that older adults in need of assistance who were more likely to receive care from informal caregivers in combination with care from formal care providers had a greater need for care as they had higher proportions of frailty. Namely, older adults who were more likely to receive care from family (both nuclear and extended) in combination with care from all types of formal care providers had higher proportions of psychological frailty and the highest proportions for physical frailty. These results are consistent with previous research by Broese van Groenou et al. (2006), Karlsson, Edberg, Westergren, and Hallberg, 2008, and Paraponaris et al. (2012) suggesting that the higher ADL and IADL dependency in older adults, the more older adults combine informal and formal care. Older adults in need of assistance who were more likely to receive care only from all types of formal care providers had higher proportions of physical frailty and were even most psychologically frail. These findings are consisted with Hoeck et al. (2011) suggesting that frail, older adults are more likely to use formal home care. Older adults in need of assistance who were more likely to receive care from informal caregivers in combination with care from the general practitioner only had the lowest proportions of physical and psychological frailty.

Second, when looking at frailty as an enabling factor (Andersen & Newman, 2005), the results indicate that social and environmental frailty affect the use of informal and formal care. Older adults in need of assistance who were more likely to receive informal care from nuclear family only were more socially frail than expected. This is also the case for older adults in need of assistance who were more likely to receive care only from formal care providers and for older adults in need of assistance who indicated to receive help from no one. Cacioppo, Hawkley, and Thisted, 2010 indicate that social support protects older adults from loneliness. Consequently, older adults with small support networks are more likely to have poor care resources (Stone & Rosenthal, 1996). This could potentially explain why older adults in need of assistance with little or no care from different types of informal caregivers had higher proportions of social frailty. Regarding environ- mental frailty, older adults in need of assistance who were more likely to receive care from family (both nuclear and extended) in combination with care from all types of formal care providers had the highest pro- portions for environmental frailty. Environmental frailty could lead to housing related risks for injuries and falls (Camilloni et al., 2011) and physical health and disease related outcomes caused by the home environment (Mack & Liller, 2010) rather than referring to a lack of material resources.

Different authors underline the importance of societal determinants in the health care use of frail, older adults (Andersen & Newman, 2005; Suanet, Broese van Groenou, & Van Tilburg, 2012). We may expect different results in other European countries as there are international differences concerning policies on home care, the practical organisation of home care and the availability of services (Genet et al., 2011). According to Suanet et al. (2012) older adults are more likely to use formal care or a combination of informal and formal care in countries where home-based services are more developed. Northern European countries like Denmark, the Netherlands and Sweden are characterised by a high level of public financing of long-term care and the individual itself has responsibilities in the provision of long-term care services (Carrieri, Di Novi, & Orso, 2017). Continental European countries like Austria, Belgium, France and Germany are characterised by moderate public financing of long-term care and the nuclear family has responsibilities in the provision of long-term care services. Southern European countries like Greece, Italy and Spain are characterised by a low level of public financing of long-term care and the extended family has many responsibilities in the provision of long-term care services. In Belgium, the financing and organisation of home care is a shared responsibility between the Belgian Federal Government and the regional authorities (Genet et al., 2011). Nursing and personal care is partly covered by a public health insurance system combined with limited out-of-pocket payments. Home care in Belgium is organised and subsidised by regional authorities, which is limited through yearly quotas (Geerts & Van den Bosch, 2012; Genet et al., 2011). Home care is delivered by competing services, which facilitate service provision. This results in the availability of services in the whole Flemish region and minimally differences in eligibility criteria. Therefore, we expect to have minimal regional differences in the results of our study (Roelands, Van Oyen, Depoorter, Baro, & Van Oost, 2003). Older adults in need of assistance who were more likely to receive care from family and all types of formal care providers, and older adults in need of assistance who were more likely to receive only formal care (from all types of formal care provi- ders) were more environmentally frail than expected. In these combi- nations the use of formal care is greater and the use of informal care smaller, which suggest that the use of home nursing and formal home assistance in particular is used by those with little material resources and probably a lower income. This underlines the importance of homecare eligibility in countries, as environmentally frail, older adults could use less formal home care in more restricted welfare regimes.

This study contributes in two ways to the care models of substitution and complementarity. First, the general practitioner is often not included into these models (Hansen, Kristoffersen, Lian, & Halvorsen, 2014). Yet, conform the study of Bolin et al. (2008), we decided to integrate the general practitioner in this study for two main raisons. Like in most Western countries, the general practitioner is an important formal care provider within the Belgian health care system. The general practitioner has a central position in the provision of care and support and often acts as gatekeeper for more specialised health care (Stijnen, Duimel-Peeters, Jansen, & Vrijhoef, 2013). One study indicates that having a general practitioner relationship of more than 2 years is a valuable substitute for complementary and alternative medical and health care providers (Hansen et al., 2014). The access of formal home assistance services is not dependent of GP care, meaning that persons do not have to go to the GP first to be able to use formal home assistance services. In Belgium, the fragmentation of the health care system is more prominent compared with other European countries and in- formal caregivers find it difficult to search within the entire care system (Willemse et al., 2016). Therefore, the general practitioner is a valuable complementary partner for informal caregivers as they can maintain an overview of the situation of the care recipient, provide information and look whether the situation is still bearable and doable for the informal caregiver.

In addition, when exploring the relationship between informal and formal care and frailty in terms of substitute or complement, this study also extents the finding of Bonsang (2009) as it does not only examine physical disabilities in the relationship between informal and formal care but also include psychological, social and environmental issues. Conforming the hypothesis of Bonsang (2009) this study suggests a relationship of complementarity between informal and formal care among frail, community-dwelling older adults, with the exception for social frailty, and when multiple formal caregivers are taken into ac- count. This highlights the complexity of the relationship between in- formal and formal care among frail, community-dwelling older adults (Kemp et al., 2013).

This study contains some limitations, each raising possibilities for future research. First, LCA identified different combinations of informal care and formal care, which did not take into account the specific care tasks provided. In this respect, it was not possible to study differences in complementarity and supplementation of care tasks between formal and informal caregivers. However, research indicates that older adults not only receive care from different caregivers but also need help for different care tasks (Johnson & Wiener, 2006; McCann & Evans, 2002). Furthermore, different care tasks are more likely to be provided according to the type of caregiver. Tennstedt, McKinlay and Sullivan (1989) indicate that secondary caregivers are less involved than primary caregivers. Nonetheless, in care tasks requiring intermittent assistance like shopping and transportation, secondary caregivers are more active. Future research should investigate the role of care tasks within the different combinations of care use. Second, the satisfaction and adequacy of the help received are not considered in this study while research indicates that this may have an influence on frailty levels. For example, Wolff and Agree (2004) indicate that the perceived quality of informal care affects the psychological wellbeing of the care recipients. Future research should take into account the satisfaction of care recipients with the help received. Third, the CFAI does not include cognitive frailty. This domain is however an important part of multi- dimensional frailty (Qingwei et al., 2015). Fourth, due to the cross-sectional nature of the data, it is not possible to make causal statements about the relationship (Field, 2009). Therefore, we cannot determine whether frailty in older adults influence the classes of care use or vice versa. Future research should provide evidence related to the temporality of the relationships.

5. Conclusion

Informal care is a major source of care for older adults in need of assistance and substitutes formal home care since the majority of the respondents are more likely to receive care from solely informal care- givers. However, older adults in need of assistance who are more likely to use informal care in a complementary way with formal care have high proportions of physical, psychological and environmental frailty. When approaching frailty as a need for care (physical and psychological frailty) and as enabling factors (social and environmental frailty) for care use, this study provides evidence on differences in informal and formal care use according to the type of frailty. Older adults in need of assistance with a higher need for care are more likely to receive care from multiple types of informal and formal caregivers as they are more physically and psychologically frail than expected. Frailty as enabling factor influences informal and formal care use as well. Namely high environmental frailty and low social frailty are related with a greater probability to use care from different types of informal and formal caregivers. These results indicate that nuances need to be made underlying the need to consider multiple informal and formal caregivers. The results of this study also show the complexity of the relationship between informal and formal care among frail, community-dwelling older adults. First, low proportions of frailty occur more often in older adults who are more likely to use care from different types of informal caregivers in combinations with care from the general practitioner. Second, psychological frailty occurs more often in older adults who are more likely to receive care only from all types of formal caregivers.

This study offers different insights in light of the evolution towards community care. The potential role of informal caregivers is recognised in this study. This study confirms the evolution towards informal care as a substitute for formal care. However, in the case of frailty, the study shows that formal care remains an important part of the care network of an older person. This suggests that the substitute relationship between informal and formal care becomes a relationship of complementarity in frail, older adults. The emphasis on informal care needs to be approached in a critical manner. Formal home care still needs to be developed alongside the informal care system. Moreover, frailty in older adults seems to limit the potential role of informal caregivers.

References

Aggar, C., Ronaldson, S., & Cameron, I. (2011). Reactions to caregiving in frailty research. *Archives of Gerontology and Geriatrics*, *53*(2), e138–e143. doi: 10.1016/j. archger.2010.07.010.

Agresti, A. (2007). *An introduction to categorical data analysis.* New Jersey: John Wiley & Sons Inc.

Andersen, R., & Newman, J. F. (2005). Societal and individual determinants of medical care utilization in the United States. *The Milbank Memorial Fund Quarterly: Health and Society*, *51*(1), 95–124. doi: 10.1111/j.1468-0009.2005.00428.x

Armstrong, J. J., Stolee, P., Hirdes, J. P., & Poss, J. W. (2010). Examining three frailty conceptualizations in their ability to predict negative outcomes for home-care clients. *Age and Ageing*, *39*(6), 755–758. doi: 10.1093/ageing/afq121

Barrett, P., Hale, B., & Butler, M. (2014). *Family care and social capital: Transitions in informal care*. Dordrecht: Springer.

Bergman, H., Ferrucci, L., Guralnik, J., Hogan, D. B., Hummel, S., Karunananthan, S., et al. (2007). Frailty: An emerging research and clinical paradigm – Issues and controversies. *The Journals of Gerontology: Series A*, *62*(7), 731–737. doi: 10.1093/gerona/62.7.731

Blomgren, J., Martikainen, P., Martelin, T., & Koskinen, S. (2008). Determinants of home-based formal help in community-dwelling older people in Finland. *European Journal of Ageing*, *5*(4), 335–347. doi: 10.1007/s10433-008-0094-4

Bolin, K., Lindgren, B., & Lundborg, P. (2008). Informal and formal care among single-living elderly in Europe. *Health Economics*, *17*(3), 393–409. doi: 10.1002/ hec.1275

Bonsang, E. (2009). Does informal care from children to their elderly parents substitute for formal care in Europe? *Journal of Health Economics*, *28*(1), 143–154. doi: 10.1016/j.jhealeco.2008.09.002

Broese van Groenou, M., Glaser, K., Tomassini, C., & Jacobs, T. (2006). Socio-economic status differences in older people's use of informal and formal help: A comparison of four European countries. *Ageing & Society*, *26*(5), 745–766. doi: 10.1017/ S0144686X06005241

Broese van Groenou, M., Jacobs, M., Zwart-Olde, I., & Deeg, D. J. H. (2016). Mixed care networks of community-dwelling older adults with physical health impairments in the Netherlands. *Health and Social Care in the Community*, *24*(1), 95–104. doi: 10.1111/hsc.12199

Byrne, D., Goeree, M. S., Hiedemann, B., & Stern, S. (2009). Formal home health care, informal care, and family decision-making. *International Economic Review*, *50*(4), 1205–1242. doi: 10.1111/j.1468-2354.2009.00566.x

Cacioppo, J. T., Hawkley, L. C., & Thisted, R. A. (2010). Perceived social isolation makes me sad: Five year cross-lagged analyses of loneliness and depressive symptomatology in the Chicago health, aging, and social relations study. *Psychology and Aging*, *25*(2), 453–463. doi: 10.1037/a0017216

Camilloni, L., Farchi, S., Rossi, P. G., Chini, F., Giorgio, M. D., Molino, N., et al. (2011). A case-control study on risk factors of domestic accidents in an elderly population. *International Journal of Injury Control and Safety Promotion*, *18*(4), 269–276. doi: 10.1080/17457300.2011.562615

Carpenter, I., Gambassi, G., Topinkova, E., Schroll, M., Finne-Soveri, H., Henrard, J. C., et al. (2004). Community care in Europe. The aged in home care project (AdHOC). *Aging Clinical and Experimental Research*, *16*(4), 259–269. doi: 10.1007/ BF03324550

Carrieri, V., Di Novi, C., & Orso, C. E. (2017). Home sweet home? Public financing and inequalities in the use of home care services in Europe. *Fiscal Studies*, *38*(3), 445–468. doi: 10.1111/j.1475-5890.2017.12138

Chappell, N., & Blandford, A. (1991). Informal and formal care: Exploring the complementarity. *Ageing & Society*, *11*(3), 299–317. doi: 10.1017/ S0144686X00004189

Colombo, F., Llena-Nozal, A., Mercier, J., & Tjadens, F. (2011). *Help wanted? Providing and paying for long-term care*. Paris: OECD health policy studies, OECD publishing.

De Donder, L., De Witte, N., Verté, D., Dury, S., Buffel, T., Smetcoren, A.-S., et al. (2014). Developing evidence-based age-Friendly policies: A participatory research project. *Research Methods Cases.* London: SAGE. doi: 10.4135/978144627305013508507

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Schols, J., et al. (2013a). The comprehensive frailty assessment instrument: Development, validity and reliability. *Geriatric Nursing*, *34*(4), 274–281. doi: 10.1016/j.gerinurse.2013.03.002

De Witte, N., De Donder, L., Dury, S., Buffel, T., Verté, D., & Schols, J. M. G. A. (2013b). A theoretical perspective on the conceptualisation and usefulness of frailty and vulnerability measurements in community dwelling older persons. *Aporia: The Nursing Journal*, *5*(1), 13–21.

Eckert, J. K., Morgan, L. A., & Swamy, N. (2004). Preferences for receipt of care among community-dwelling adults. *Journal of Aging and Social Policy*, *16*(2), 49–65. doi: 10.1300/J031v16n02_04

Field, A. (2009). *Discovering statistics using SPSS*. London: SAGE publications Ltd.

Gannon, B., & Davin, B. (2010). Use of formal and informal care services among older people in Ireland and France. *European Journal of Health Economics*, *11*(5), 499–511. doi: 10.1007/s10198-010-0247-1

Geerts, J., & Van den Bosch, K. (2012). Transitions in formal and informal care utilisation amongst older Europeans: The impact of national contexts. *European Journal of Ageing*, *9*(1), 27–37. doi: 10.1007/s10433-011-0199-z

Genet, N., Boerma, W. G. W., Kringos, D. S., Bouman, A., Francke, A. L., Fagerström, C., et al. (2011). Home care in Europe: A systematic literature review. *BMC Health Services Research*, *11*, 207. doi: 10.1186/1472-6963-11-207

Gobbens, R. J. J., Luijkx, K. G., Wijnen-Sponselee, M. T., & Schols, J. M. G. A. (2010). In search of an integral conceptual definition of frailty: Opinions of experts. *Journal of the American Medical Directors Association*, *11*(5), 338–343. doi: 10.1016/j.jamda.2009.09.015

Greene, V. L. (1983). Substitution between formally and informally provided care for the impaired elderly in the community. *Medical Care*, *21*(6), 609–619.

Hanaoka, C., & Norton, E. C. (2008). Informal and formal care for elderly persons: How adult children’s characteristics affect the use of formal care in Japan. *Social Science & Medicine*, *67*(6), 1002–1008. doi: 10.1016/j.socscimed.2008.05.006

Hansen, A. H., Kristoffersen, A. E., Lian, O. S., & Halvorsen, P. A. (2014). Continuity of GP care is associated with lower use of complementary and alternative medical providers: A population-based cross-sectional survey. *BMC Health Services Research*, *14*, 629. doi: 10.1186/s12913-014-0629-7

Hoeck, S., François, G., Geerts, J., Van der Heyden, J., Vandewoude, M., & Van Hal, G. (2011). Health-care and home care utilization among frail elderly persons in Belgium. *European Journal of Public Health*, *22*(5), 671–676. doi: 10.1093/eurpub/ckr133

Jacobs, M., Van Tilburg, T., Groenewegen, P., & Broese van Groenou, M. (2016). Linkages between informal and formal care-givers in home-care networks of frail older adults. *Ageing & Society*, *36*(8), 1604–1624. doi: 10.1017/S0144686X15000598.

Jacobs, M. T., Broese van Groenou, M. I., Aartsen, M. J., & Deeg, D. J. H. (2018). Diversity in older adults' care networks: The added value of individual beliefs and social network proximity. *Journals of Gerontology: Series B*, *73*(2), 326–336. doi: 10.1093/geronb/gbw012

Johnson, R. W., & Wiener, J. M. (2006). *A profile of frail older Americans and their caregivers*. Washington DC: Urban institute.

Kahn, R. L., & Antonucci, T. C. (1980). Convoys over the life course: A life course approach. In P. B. Baltes, & O. Brim (Eds.). *Life span development and behavior* (pp. 253–286). New York: Academic Press.

Kalwij, A., Pasini, G., & Wu, M. (2014). Home care for the elderly: The role of relatives, friends and neighbors. *Review of Economics of the Household*, *12*(2), 379–404. doi: 10.1007/s11150-012-9159-4.

Karlsson, S., Edberg, A.-K., Westergren, A., & Hallberg, I. R. (2008). Functional ability and health complaints among older people with a combination of Public and informal care vs. Public care only. *Scandinavian Journal of Caring Sciences*, *22*(1), 136–148. doi: 10.1111/j.1471-6712.2007.00549.x

Keating, N., & Dosman, D. (2009). Social capital and the care networks of frail seniors. *Canadian Review of Sociology*, *46*(4), 301–318. doi: 10.1111/j.1755-618X. 2009.01216.x

Keating, N., Otfinowski, P., Wenger, C., Fast, J., & Derksen, L. (2003). Understanding the caring capacity of informal networks of frail seniors: A case for care networks. *Ageing & Society*, *23*(1), 115–127. doi: 10.1017/S0144686X02008954

Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: Theorizing intersections of formal and informal care. *Journal of Aging Studies*, *27*(1), 15–29. doi: 10.1016/j.jaging.2012.10.002

Kemper, P. (1992). The use of formal and informal home care by the disabled elderly. *Health Services Research*, *26*(4), 421-451.

Koehly, L. M., Ashida, S., Schafer, E. J., & Ludden, A. (2015). Caregiving networks – Using a network approach to identify missed opportunities. *Journals of Gerontology, Series B*, *70*(1), 143-154. doi: 10.1093/geronb/gbu111.

Ku, L.–J. E., Liu, L.–F., & Wen, M.-J. (2013). Trends and determinants of informal and formal caregiving in the community for disabled elderly people in Taiwan. *Archives of Gerontology and Geriatrics*, *56*(2), 370–376. doi: 10.1016/j.archger. 2012.11.005.

Larsson, K., & Silverstein, M. (2004). The effects of marital and parental status on in- formal support and service utilization: A study of older Swedes living alone. *Journal of Aging Studies*, *18*(2), 231–244. doi: 10.1016/j.jaging.2004.01.001.

Litwin, H., & Attias-Donfut, C. (2009). The inter-relationship between formal and in- formal care: A study in France and Israel. *Ageing and Society*, *29*(1), 71–91. doi: 10.1017/S0144686X08007666.

Mack, K. A., & Liller, K. D. (2010). Home injuries: Potential for prevention. *American Journal of Lifestyle Medicine*, *4*(1), 75-81. doi: 10.1177/1559827609348476

Markle-Reid, M., & Brown, G. (2003). Conceptualizations of frailty in relation to older adults. *Journal of Advanced Nursing*, *44*(1), 58-68. doi: 10.1046/j.1365-2648. 2003.02767.x

McCutcheon, A. L. (1987). *Latent class analysis*. Newbury Park, CA: Sage.

Moscovice, I., Davidson, G., & McCaffrey, D. (1988). Substitution of formal and informal care for the community-based elderly. *Medical Care*, *26*(10), 971–981.

Nylund, K. L., Asparouhov, T., & Muthèn, B. O. (2007). Deciding on the number of classes in latent class analysis and growth mixture modeling: A Monte Carlo simulation study. *Structural Equation Modeling*, *14*(4), 535–569. doi: 10.1080/10705510701575396

Paraponaris, A., Davin, B., & Verger, P. (2012). Formal And informal care for disabled elderly living in the community: An appraisal of French care composition and cost. *European Journal of Health Economics*, *13*(3), 327–336. doi: 10.1007/s10198-011-0305-3.

Qingwei, R., Zhuowei, Y., Ma, C., Zhijun, B., Jin, L., & Wei, H. (2015). Cognitive frailty, a novel target for the prevention of elderly dependency. *Ageing Research Reviews*, *20*, 1–10. doi: 10.1016/j.arr.2014.12.004.

Rodriguez, M. (2014). Use of informal and formal care among community dwelling dependent elderly in Spain. *European Journal of Public Health*, *24*(4), 668–674. doi: 10.1093/eurpub/ckt088.

Roelands, M., Van Oyen, H., Depoorter, A., Baro, F., & Van Oost, P. (2003). Are cognitive impairment and depressive mood associated with increased service utilisation in community-dwelling elderly people? *Health and Social Care in the Community*, *11*(1), 1-9. doi: 10.1046/j.1365-2524.2003.00401.x

Ryan, L. H., Smith, J., Antonucci, T. C., & Jackson, J. S. (2012). Cohort differences in the availability of informal caregivers: Are the boomers at risk? *The Gerontologist*, *52*(2), 177–188. doi: 10.1093/geront/gnr142

Sigurdardottir, S. H., & Kareholt, I. (2014). Informal and formal care of older people in Iceland. *Scandinavian Journal of Caring Sciences*, *28*, 802–811. doi: 10. 1111/scs.12114

Stabile, M., Laporte, A., & Coyte, P. C. (2006). Household responses to public home care programs. *Journal of Health Economics*, *25*(4), 674–701. doi: 10.1016/j. jhealeco.2005.03.009

Stijnen, M. M. N., Duimel-Peeters, I. G. P., Jansen, M. W. J., & Vrijhoef, H. J. M. (2013). Early detection of health problems in potentially frail community-dwelling older people by general practices - Project [G]OLD: Design of a longitudinal, quasi-experimental study. *BMC Geriatrics*, *13*, 7. doi: 10.1186/1471-2318- 13-7.

Stone, L., & Rosenthal, C. (1996). Profiles of the social networks of Canada's elderly: An Analysis of 1990 General social survey data. In H. Litwin (Ed.). *The social networks of older people: A Cross-national analysis* (pp. 77–97). Westport: Praeger Publishers.

Suanet, B., Broese van Groenou, M., & Van Tilburg, T. (2012). Informal and formal home-care use among older adults in Europe: Can cross-national differences be explained by societal context and composition? *Ageing & Society*, *32*(3), 491-515. doi: 10.1017/S0144686X11000390

Tennstedt, S. L., McKinlay, J. B., & Sullivan, L. M. (1989). Informal care for frail elders: The role of secondary caregivers. *The Gerontologist*, *29*(5), 677-683. doi: 10.1093/geront/29.5.677.

United States, Health Care Financing Administration, Office of Policy Analysis. (1981). *Long-term care: Background and future directions.* Retrieved on 7 December 2016, from https://archive.org/details/longtermcareback19unit

van Assen, M. A. L. M., Pallast, E., El Fakiri, F., & Gobbens, R. J. J. (2016). Measuring frailty in Dutch community-dwelling older people: Reference values of the Tilburg frailty indicator (TFI). *Archives of Gerontology and Geriatrics*, *67*, 120–129. doi: 10.1016/j.archger.2016.07.005

Van den Berg, B., Brouwer, W. B. F., & Koopmanschap, M. A. (2004). Economic valuation of informal care. An overview of methods and applications. *European Journal of Health Economics*, *5*(1), 36–45. doi: 10.1007/s10198-003-0189-y

Van Der Ark, L. A., & Richards, G. (2006). Attractiveness of cultural activities in European cities: A latent class approach. *Tourism Management*, *27*(6), 1408–1413. doi: 10.1016/j.tourman.2005.12.014

Van Houtven, C. H., & Norton, E. C. (2004). Informal care and health care use of older adults. *Journal of Health Economics*, *23*(6), 1159–1180. doi: 10.1016/j. jhealeco.2004.04.008

Vermunt, J. K. (1997). *LEM: A general program for the analysis of categorical data*. Retrieved on 7 December 2016, from http://www.camri.uqam.ca/camri/app/statistics/LCA/LEM/manual.pdf

Wiles, J. L., Leibing, A., Guberman, N., Reeve, J., & Allen, R. E. S. (2011). The meaning of 'Ageing in Place' to older people. *The Gerontologist*, *52*(3), 357–366. doi: 10.1093/geront/gnr098

Willemse, E., Anthierens, S., Farfan-Portet, M. I., Schmitz, O., Macq, J., Bastiaens, H., et al. (2016). Do Informal caregivers for elderly in the community use support measures? A qualitative study in five European countries. *BMC Health Services Research*, *16*, 270. doi: 10.1186/s12913-016-1487-2.

Wolff, J. L., & Agree, E. M. (2004). Depression among recipients of informal care: The effects of reciprocity, respect, and adequacy of support. *Journal of Gerontology: Series B*, *59*(3), S173–S180. doi: 10.1093/geronb/59.3.S173

Chapter 7. Meanings of care convoys: the structure, function and adequacy of care networks among frail, community-dwelling older adults

---

Manuscript submitted

Lambotte, D., Smetcoren, A.-S., Zijlstra, G. A. R., De Lepeleire, J., De Donder, L., Kardol, M. J. M., & the D-SCOPE Consortium. Meanings of care convoys: the structure, function and adequacy of care networks among frail, community-dwelling older adults.

Abstract

Several scholars have proposed to use the convoy of care model to study care networks of (frail) older individuals. This study examines community-dwelling older adults' experiences of their care convoy, how care convoys change over time and perceived (positive) outcomes. A secondary analysis among 65 qualitative interviews with frail, community-dwelling older adults demonstrate a great variety in the composition of care convoys. Participants were often actively involved in their care convoy and valued to social/relational aspect of care. Care and support covered a wide range of activities, with some activities being provided by specific types of caregivers. Participants expressed the adequacy of their care convoys in terms of satisfaction and sufficiency. Noteworthy, participants who were satisfied with their care convoy did not necessarily receive sufficient help. Policies and practice should recognise the relational aspect of care, the complex interplay between all actors and the dynamicity of care convoys.

Keywords

Older adults; frailty; care convoys; qualitative research; thematic analysis; secondary analysis

1. Introduction

There is an increasing focus in international literature on care and support of frail, community-dwelling older adults (José, Barros, Samitca, & Teixeira, 2016). With increasing age, older adults can face physical, cognitive, psychological, social and environmental problems (Grenier, 2007; Dury et al., 2018). When experiencing a need for care and support, informal caregivers (e.g. spouse, children, friends, neighbours) and formal caregivers (e.g. general practitioner, home nurse, cleaning services) play a crucial role for the continuance of 'ageing in place'. This desire to stay at home for as long as possible is not only the preference of most (frail) older adults (Smetcoren, 2015) but also became a policy strategy for many European governments in order to cope with an ageing society (Means, Richards, & Smith, 2008). Due to austerity measures, formal care services are confronted with limited financial resources and governments are encouraging informal caregivers to support frail, older adults at home (Broese van Groenou & De Boer, 2016). At the same time different demographic changes (e.g. declining family size) and societal developments (e.g. women's labour force participation) limit the availability of children as primary informal caregivers (Agree & Glaser, 2009). Therefore, the proportion of frail, community-dwelling older adults receiving care and support from a diverse range of informal and formal caregivers is likely to increase in the coming years (Jacobs, Broese van Groenou, Aartsen & Deeg, 2018). The Flemish Senior Citizens policy plan 2015-2020 indicates that care is no longer solely the responsibility of professionals but a shared responsibility between care recipients, their social networks and professionals (Flemish government, 2015). In addition to the Flemish Senior Citizens policy plan 2015-2020, a Flemish informal care plan 2016-2020 has been developed, which promote informal care and stimulate health and social care professionals to take into account individuals' (social) environment (Vandeurzen, 2016).

A diverse collection of individuals who provide instrumental and emotional support to older adults because of their long-term health problems or functional limitations are labelled 'care networks' (Keating, Otfinowski, Wenger, Fast, & Derksen, 2003). To date, several studies explored care networks of community-dwelling older adults. Some of these studies suggest moving beyond a dyadic perspective for informal and formal care and the classical distinction between receiving (1) informal care only, (2) formal care only or (3) both informal and formal care (Broese van Groenou, Jacobs, Zwart-Olde, & Deeg, 2016; Lambotte et al., 2018; Jacobs et al., 2018). For example, Lambotte et al. (2018) identified eight combinations of informal and formal care use in community-dwelling older adults. For example, in one of the eight care networks, older adults were more likely to receive care from family, friends/acquaintances, neighbours and the general practitioner. Other studies highlight the need to understand the linkages between informal and formal care (Ayalon & Roziner, 2016; Jacobs, Van Tilburg, Groenewegen, & Broese van Groenou, 2016). Existing theoretical models like the substitution model (Greene, 1983), the task specificity model (Litwak, 1985), the hierarchical compensation theory (Cantor, 1991) and the complementary model (Chappell & Blandford, 1991) are considered being too limited. In these conventional models, informal and formal care are regarded as separate systems rather than potentially overlapping arrangements and assume family care as preferred by care recipients (Ayalon, Halevy-Levin, Ben-Yizhak, & Friedman, 2013; Ward-Griffin & Marshall, 2003). These models also ignore care recipients as potentially active actors within their own care and support (Allen & Cambrone, 2003; Kemp, Ball, & Perkins, 2013; Porter, 2005). Furthermore, they do not reflect the dynamic nature of care networks nor the increasing, complex needs of frail individuals (Kemp et al., 2013). In reaction to these gaps, Kemp et al. (2013) have put forward 'the convoy of care model' as a new, alternative approach for studying care networks.

The convoy of care model acknowledges the complexity and dynamicity of care networks. For their approach Kemp et al. (2013) modified and expanded the convoy model of social relations (e.g. Kahn & Antonucci, 1980) with insights from the life course theory (e.g. Elder, 1998), feminist gerontology (e.g. Calasanti, 2009; Ward-Griffin & Marshall, 2003), social ecology (Moos, 1979) and symbolic interactionism (e.g. Blumer, 1969). Care convoys are defined as "*the evolving collection of individuals who may or may not have close personal connections to the recipient or to one another, but who provide care, including help with activities of daily living (IADLs), socio-emotional care, skilled health care, monitoring and advocacy*" (Kemp et al., 2013, p. 18). A convoy of care contains all of the people who provide support, including informal and formal caregivers. Care recipients are also directly involved in care relationships and are defined as active participants. Care convoy properties comprise structure (e.g. size, homogeneity, stability), function (e.g. support given, received, exchanged) and adequacy (e.g. satisfaction with support). According to Kemp et al. (2013) each individual's care convoy has properties unique in structure and function, both of which can influence its adequacy. Care convoy properties change and evolve over time through negotiations, and are influenced by personal (e.g. gender, race, level of frailty) and societal (e.g. role expectations, norms) characteristics. Care convoys can have outcomes for the care recipient (e.g. wellbeing), informal caregivers (e.g. level of care burden) and formal caregivers (e.g, job satisfaction).

To our knowledge, the convoy of care model has only been explored in the context of assisted living (Kemp et al., 2013, 2017, 2018). Within this context care convoys often involve informal caregivers (e.g. family and friends), assisted living staff and multiple external care workers (Kemp et al., 2013, 2018). Residents are often care partners and participate in self-care and care management (Kemp et al., 2018). Several factors (e.g. social and material resources, caregivers' attitudes and beliefs) affect care convoys and either facilitate or constrain quality of life and quality of care (Kemp et al., 2018).

To date, there is little empirical evidence concerning care networks among community-dwelling older adults (Verver, Merten, Robben, & Wagner, 2018). The study at hand addresses this research gap by exploring the meanings and experiences of frail, community-dwelling older adults concerning the structure, function and adequacy of their care convoy, how their care convoy change over time and what the experienced (positive) outcomes of care convoy are for these persons.

2. Method

2.1. Research design

The present study is a secondary analysis on qualitative data of the Detection, Support and Care for Older people: Prevention and Empowerment (D-SCOPE) project (see Dury et al., 2018 for a detailed description). D-SCOPE aimed to explore (a) the lived experiences of community-dwelling older adults at risk of frailty about frailty, quality of life, care and support, mastery and meaning in life, (b) balancing factors that might influence frailty and outcome variables such as informal and formal care, and (c) life changes and turning points and how these affect frailty, quality of life, care and support, meaning in life and mastery. Between November 2015 and March 2016, 121 community-dwelling older adults at risk of frailty were interviewed in Flanders and Brussels. The Human Sciences Ethical Commission of the Vrije Universiteit Brussel approved the research (Ref: ECHW_031).

2.2. Procedures and data collection

Community-dwelling older adults (60+) at risk of frailty were recruited by using a purposive sampling procedure. Five homecare organisations recruited 64 participants from their client list and 57 participants were recruited via snowball sampling. Participants were included based on risk profiles for multidimensional frailty (Dury et al., 2017). Exclusion criteria were hospitalisation and the person's incapacity to participate in the study (e.g. due to physical exhaustion, inability to provide adequate answers). Also, persons who received a dementia diagnosis, as determined by a doctor (specialist or general practitioner) were excluded.

Eligible participants received written information about the study and signed an informed consent agreement before participation. They were informed about the voluntary nature of their involvement, their right to refuse to participate and the confidentiality of their responses. Once the participants signed the informed consent form, trained researchers administered a quantitative questionnaire, and a qualitative, in-depth interview in the language of the participant's choice. The quantitative questionnaire contained the Comprehensive Frailty Assessment Instrument Plus (CFAI-Plus) (De Roeck et al., 2018), the Montreal Cognitive Assessment Instrument (MoCA) (Nasreddine et al., 2005) and numeric rating scales for quality of life, care and support, meaning in life and mastery. The same researchers subsequently held semi-structured interviews with open-ended questions with the participants. The qualitative data collection comprised questions on experiences of frailty, frailty balance, care and support, mastery and life changes and turning points. The interviews were conducted in Dutch or French by one of the researchers. For the participants with a migration background, an interpreter attended the interviews when necessary. The interviews took place in participants' homes.

All interviews were digitally recorded and transcribed ad verbatim. All data were anonymised.

2.3. Participants' characteristics

The present study (N = 65) used qualitative data from participants who had at least one informal caregiver (e.g. family member, friend or neighbour) and who scored medium to high frail on at least one of the five domains of the CFAI-Plus (De Roeck et al., 2018). The CFAI-Plus, an extended version of the CFAI (De Witte et al., 2013), is a self-assessment instrument that measures five domains of frailty: physical, cognitive, psychological, social and environmental frailty (De Roeck et al., 2018). Physical frailty comprises limitations in physical activities due to health problems. Psychological frailty includes mood-disorders and emotional loneliness. Social frailty comprises social loneliness and lack of social support network. Environmental frailty includes housing conditions. Cognitive frailty assesses subjective cognitive complaints. Based on the results of the CFAI-Plus, older adults were grouped into 1) not-to-low frail, 2) low-to-medium frail, and 3) medium-to-high frail, for each domain of frailty (De Roeck et al., 2018).

The average age of the participants in the study was 79.9 years (SD = 8.7; range from 60 years to 95 years). 64.6% was female (N = 42). Regarding the marital status of the participants, 66.2% were widowed (N = 43), 21.5% were married (N = 14), 9.2% were divorced (N = 6), and 3.1% were never married (N = 2). 18.5% of the participants had a migration background (N = 12). The prevalence of medium to high frail in the frailty domains were: 42.2% physically frail (N = 27), 83.9% cognitively frail (N = 52), 32.3% psychologically frail (N = 20), 15.4% socially frail (N = 10) and 21.9% environmentally frail (N = 14).

2.4. Data analysis

A secondary analysis using thematic (content) techniques was conducted on the data and incorporated both deductive, concept-driven coding, and inductive, data-driven coding (Cho & Lee, 2014; Fereday & Muir-Cochrane, 2006; McGraw et al., 2017). For the deductive coding, a codebook was developed from the research literature, which consisted of the main components of the convoy of care model (Kemp et al., 2013): (1) structure, (2) function, (3) adequacy, (4) life changes and turning points with regard to participants' care convoy, and (5) perceived (positive) outcomes of care convoys for participants. These were the main labels. Within this template, inductive coding took place for the creation of sublabels in the main labels, which allowed new themes to emerge from the interviews.

Main labels of the codebook based on the convoy of care model (Kemp et al., 2013):
(1) Structure: composition of care convoys, changes in care convoys (2) Function: type of support given, received, exchanged in care convoys (3) Adequacy: the quality of care convoys (4) Changes within participants' care convoy (5) (Positive) outcomes: results/consequences of care convoys

Multiple researchers were involved in the coding process. Interviews were individually coded by the main researcher. Consensus on the codebook was achieved through discussion and involved two additional experts in care and support. The final codebook and findings were discussed with all researchers.

The interviews were coded using the software program MAXQDA. This program facilitates thematic content analyses (Oliveira, Bitencourt, Teixeira, & Santos, 2013).

3. Results

3.1. Properties of care convoys: structure

The interviews revealed a great variety in the structure of participants' care convoy. Participants often indicated to receive informal and formal care from different individuals and types of organisations.

Regarding informal care, participants explained receiving care and support from family caregivers (e.g. spouse, children, grandchildren, siblings), friends and neighbours. Participants often labelled their spouse and children as their primary informal caregivers. In some cases, also friends and neighbours were actively mentioned, whether or not family caregivers were available.

As a participant indicated that a friend took care of her: 'Especially for the administration. She takes good care of me. We also call each other, and she always brings me good things to eat. She has my credit card and she does what she wants with it. I trust her completely' (woman, 81 years, widowed).

In some care convoys a primary informal caregiver provided most of the informal care, in other care convoys several informal caregivers were present and had shared responsibilities.

Regarding formal care, participants explained receiving care and support from a wide range of professionals and types of organisations: the general practitioner, physiotherapist, home nurse, home cleaning, etc. Besides these rather 'typical' formal care services, participants mentioned receiving assistance from social service centres, 'meals on wheels', specialised transport, etc., and they declared to use assistive tools like a personal alarm system, a walking stick, rollator or stairlift.

Due to reduced mobility, participants expressed their incapacity to leave their home independently. Therefore, several local merchants (e.g. bakery, pharmacy, hairdresser) delivered their products and services at home. One participant explained: 'The pharmacist delivers my medication in the morning. He puts six pills in this box [points to his pill box]. He comes every day. And he also contacts the doctor for the medication' (man, 81 years, widowed). Some participants moved into service flats (i.e. form of housing with support and care facilities) and considered this as a type of 'professional support'.

Some care convoys were small containing one or two caregivers, other care networks comprised multiple informal and/or formal caregivers. The latter participants often received more intensive care and support on a more regular basis.

Some care situations were characterised by the interplay between care recipient, informal and/or formal caregivers. First, in some cases informal caregivers noticed the care needs of the participants and looked for formal care possibilities. Informal caregivers often involved the participants, for example by negotiating care possibilities and asking for their opinion and approval. Second, participants negotiated with their informal caregivers the professional advices. As an 88-year old widow explained: 'I asked my daughter on the phone, "Wouldn't it be better to stop with the injections? I see no progress, I even feel more pain in my groin area"'. Sometimes informal caregivers interfered and advised the participants no to follow medical recommendations. Third, formal caregivers reported to informal caregivers when something seemed out of the ordinary, and vice versa.

3.2. Properties of care convoys: function

Throughout the interviews, participants indicated they took care of themselves, cared for others, received and exchanged care.

Self-care

Participants emphasised the importance of caring for themselves as much as possible in order to reduce their dependency on others. In general, participants tried to maintain and increase their dependency in two ways. First, participants adapted and found new ways to manage their daily tasks, so they would need less or no assistance.

As stated by an 81-year old married man: 'I still do the grocery shopping by myself. I cannot lift 6 bottles of 1.5 litre water in one time. Or 6 cartons of milk. So, I have a pocket knife in my car. I take it with me, I cut the package open and I put one bottle at a time in my shopping cart and one bottle at a time in the car. And I do this at home too'.

Second, participants tried to exert mastery over their informal and/or formal care and support. By taking action (e.g. making decisions, asking for care, organising care and support provision) participants ensured their care preferences and needs were met adequately. For example, one participant decided to have lunch at the local service centre to meet others: ‘When I feel good, I go to the local service centre to have lunch, this way I have some social contact’ (woman, 72 years, widowed). Within this aspect, informal caregivers were often involved. Participants consulted their informal caregivers and tried to convince them that the way they acted was what was best for them. In contrast, other participants indicated that they chose to ignore their informal caregivers at moments they preferred them not to be involved. One participant explained: ‘You sometimes have to pretend you did not hear it, when certain things are said. And keep on doing your own thing’ (interpreter of woman with migration background, 86 years, widowed).

Although participants were often in charge of their own care and support, this was not always the case and some participants explained how their informal or formal caregivers took over the care management. Nevertheless, participants often demonstrated active involvement in both informal and formal care relationships. First, participants indicated to have a say in the care and support, for example by telling their (in)formal caregivers what to do and asking questions. Caregivers also asked what was needed or how things needed to be done. Second, participants explained to participate in the care activity itself. Even though this was principally the case with their informal caregivers, sometimes participants also contributed that way in formal care settings. A 72-years old widow said: ‘And when the cleaning lady comes, I say “I will take care of this”, but I cannot do anything in heights and she knows so she responds, “normally I’m paid to do that”. But actually, I want to do it to prove to myself that I am still worth something and that I’m not a lazy person’.

Participants also liked performing the care activities together with their caregivers because of the social interactions, i.e. talking and spending time with each other. Many participants expressed a wish to be involved in their care and support, this way they maintain a sense of control and autonomy. In some cases, participants did not receive the opportunity to be involved. One participant explained how her general practitioner discussed the care situation with her daughter without involving her: ‘Sometimes he [general practitioner] calls my daughter [and says] “Madam, I’m here with your mother. There is not much progress with that medication. I suggest doing a scan.” And subsequently I receive a date’ (woman, 80 years, widowed).

One participant deliberately chose to receive formal care which actually was not needed (anymore). She was able to take care of herself but decided to keep using formal care services as a reassurance, a form of social control: 'Someone already came to prepare my meal. The nurse will come to take my blood pressure, prepare my medication and check if everything is alright. Nobody will come until the evening, to put me in bed at ten o'clock. I might be able to do all this on my own, but I do not want to do it because of what happened in the past. My disease can reoccur at any time and I could lie here for days if nobody would come' (woman, 85 years, widowed).

Some participants emphasised self-care as a way to minimise the burden on their informal caregivers. A 91-years old widow expressed: 'I have a little garden. I plant vegetables and I also clean them. I cannot leave it all for my son'.

Giving care

Participants in some cases cared for others while receiving care and support themselves. When taking care of loved ones with a high demand for care (e.g. disabled child or spouse) participants indicated to carry a great burden. They felt neither understood nor assisted by their social environment including their informal caregivers and expressed worries and feelings of exclusion. One participant took care of her son who had a mental disorder and explained she lacked support from her other children: 'Apparently, it is too heavy for the other children. And they leave me with it. You know, they have their own household and busy schedules' (woman, 84 years, widowed). Some of them appealed to formal care and experienced this as a relief because they could not provide the necessary care and support anymore. One participant who was informal caregiver for his wife explained: 'I receive home care. I do the grocery shopping, but I can't cook anymore. She [formal caregiver] prepares the vegetables and puts the food in boxes that I can warm up in the microwave. That is a relief. But I still have a lot of worries' (man, 88 years, married).

Some participants helped others with less intensive care tasks, for example when helping neighbours or taking care of (great-)grandchildren. As an 87-years old widow indicated: 'As the daughter lives too far away I suggested her to do it. I just have to cross the street and give her the eye drops'. Those care tasks were considered as meaningful and useful.

Receiving care

Participants explained to require care and support within various activities, including personal care (e.g. preparing medications, bathing, dressing and undressing), home care (e.g. preparing meals, administration, grocery shopping, housecleaning), transportation and socio-emotional support. According to the participants, personal care and housecleaning were tasks mainly delivered by formal caregivers, and informal caregivers supported them principally in other home activities such as administration, transportation and socio-emotional support. Participants explained how informal caregivers also helped and supported them in additional tasks such as carrying out house modifications.

A 91-years old widow explained: 'My daughter-in-law takes care of everything. For example, she closed the gas fire. It does not work anymore, so I cannot accidently activate it. She bought me a little oven and also a dustbin for inside because I put the garbage on the terrace. No, it is comfortable now. Absolutely, I feel like a queen'.

Family members cared more extensively for the participants while friends and neighbours provided less intensive care and support, as they especially helped with 'little' things. In some cases, this distinction was present for the same activity. As one participant explained for grocery shopping: 'When my daughter comes, she asks me one day in advance what I need. So, she brings me what I need for a little while. And my neighbour buys bread, little things like this' (woman, 80 years, divorced).

Although, there are also exceptions in which neighbours take on a more extensive role. As one of the participants indicated to rely on his neighbour for almost everything: 'Cooking, maintaining the house from top to bottom. Shopping, my payments, … I do not think she can do more because there is not much else she can do' (man, 82 years, divorced).

In general, participants valued the social contacts within their informal and formal care relationships and attributed positive outcomes to these social relations. One participant indicated she felt less lonely and depressed: 'I suffered from a depression one year ago. So, I went to the hospital and upon my return I started home care. Miraculously, after 6 months I managed to overcome my depression. It is probably due to the home care team because seeing and speaking 3 times a day to someone, the human contact, it must have been my cure I think' (woman, 91 years, widowed).

With regard to informal care, participants explicitly appreciated the moments with their informal caregivers that went beyond the care and support tasks (e.g. going to the restaurant, go shopping together).

With regard to formal care, participants enjoyed sharing a cup of coffee with their formal caregivers, which gave them a moment to talk about personal stories. An 85-years old married woman explained: ‘When they come, the first thing we do is drink coffee. And then they ask, “What do you want us to do?” And before they leave, we drink coffee again’. In some cases, participants developed meaningful relationships with their formal caregivers. An 80-years old widow explained she went on an excursion with her cleaning lady: ‘She called me last year, “We are going to visit the capital by train. Do you want to join?” Yes! And we went to Brussels by train’. Some types of formal care also caused informal social contacts to increase. One participant said about going to the day-care centre: ‘Yes, I like that. I like to be among people. And we chat, play cards. You see people come and go. You have lunch together’ (woman, 81 years, widowed). In some cases, despite the presence of informal caregivers, participants valued the relationship with formal caregivers more.

Exchanging care

Participants demonstrated reciprocity within their care relationships and tried to do something in return for their caregivers in several ways. First, participants provided gifts or even financial support. Second, reciprocity arose in the form of care relationships. This was often the case for spouses who took care of each other. But this also occurred in other relationships. For example, one 83-years old married man helped his daughter by looking after her disabled child: ‘We help her as much as possible. When she has to leave in the evening’. Participants also expressed a sense of reciprocity regarding assistance from their neighbours. A 76-years old married man explained: ‘If they need me or if I can do anything, I will do it. And it also works the other way around. If I ask something, then I know I can count on them’. Finally, participants expressed reciprocity by showing gratitude and respect to their caregivers.

3.3. Properties of care convoys: adequacy

The participants were generally very positive about their care convoy. Participants expressed the adequacy of their care convoy in two ways: the extent to which they were satisfied of their care convoy (quality) and the extent to which their care convoy were sufficient (quantity).

Satisfaction

Participants mentioned several aspects which contributed to the extent to which participants were satisfied with their care convoy. First, participants appreciated being treated with respect and commitment. As one participant explained how her formal caregiver did not respect her cultural traditions: ‘With the Turkish people you need to take off your shoes when you enter. And she likes it very much when people do this, and she even offers little slippers instead. The last time a Moroccan nurse arrived, Mrs. asked “Can you take off your shoes?” And the nurse refused to do it’ (translator for woman, 60 years, married).

Another participant stated how her informal caregiver emphasised her limitations and how this made her feel bad:

‘I used my portable toilet and my sister said, “I am first going to carry that outside because it stinks in here.” I cannot do anything about that, I cannot carry it outside by myself. “You have to open the windows”, she said. To which I replied, “Open the windows? Then they [formal caregivers] have to wait and close the windows again, because I cannot.” “Yes, that is true”, she said. And you know what I also responded to her? “You may still be happy that I do not wet my pants.” She said, “You do not have to take it so seriously.” But it was said, and I really felt hurt’ (woman, 87 years, widowed).

Second, participants valued the possibility to appeal on the availability of their caregivers if something would happen. This was mainly the case for informal caregivers due to their proximity. Participants explained how living with or close to their informal caregivers made them feel safe and reassured: ‘You are more relaxed. If something happens, you know where to go, you know who to call, who can help you. That is what matters to me’ (man, 76 years, married). Participants experienced this reassurance also in ‘alternative’ formal home care services like Care 24 (i.e. a project of home nursing coming also during the night) and FocusPlus (i.e. alternative housing arrangement with personal alarm system directly connected to professionals working in the building). An 82-years old divorced man indicated that Care 24 reassured his informal caregivers as well: ‘I am lucky that those nurses come day and night. They also come twice during the night. So, in fact that is a reassurance. And a reassurance for her [i.e. informal caregiver] too’.

However, living close by was not always a guarantee for instant help: ‘My daughter lives nearby. I cannot complaint about her. But sometimes I assumed that she would help her father a bit more. I do not hear of her. It is not always like this, but for example yesterday and the day before I did not see her’ (man, 90 years, widowed).

Finally, participants were not satisfied of some aspects related to formal care specifically. The first aspect concerned the time at which formal caregivers provided care. One participant explained: ʻA nurse comes twice a week. In the beginning she came at 10 or 11 o'clock. That was not bearable because it forced me to stay in my pyjamas for so long. And now she comes around 9 o'clock. This morning she was here at 8 o'clock' (woman, 72 years, widowed). Participants were not always able to trust formal caregivers because they switched. Related to this aspect, some participants indicated that you needed to be lucky because they felt like not all formal caregivers did their job well.

Sufficiency

Participants experienced care shortages in both informal and formal care arrangements. Some participants stated, while being satisfied with their care and support, that they did not receive enough assistance.

Within informal care settings, participants explained how their informal caregivers were not always able to give sufficient care and support due to a lack of time. Informal caregivers often had a job, their own household, etc. In some cases, informal caregivers lived far from the participants. As an 80-years old widow indicated when needing help for transportation: 'If she [daughter] is on duty, she must stay at the hospital. And then I do not know whether my other daughter would drive from the coast for me. So, what should I do? I call a taxi'.

Also, participants experienced boundaries when asking for informal help. Participants noticed their informal caregivers were burdened and exhausted. They felt guilty about being dependent on their informal caregivers. 'If I see that it does not go well anymore, I will ask to leave. I wish to stay at home for as long as possible. But if I see this is too difficult for her [daughter], I do not want to do that to her either. Then she does not have a life anymore. I feel already bad for her' (woman, 94 years, widowed). Participants also explained their informal caregivers were sometimes frail and in need of assistance themselves.

Within formal care settings, participants explained how the necessary administration and long waiting lists discouraged them to arrange care. One 72-year old widow explained: 'I applied for that once. There is a waiting list of at least 6 months. I said "Then leave it. I will handle it myself." It is always the same, if you ask for something, you are put on a waiting list'. Subsequently some participants received insufficient formal care due to their low income and the high price of some care possibilities and assistive means.

3.4. Changes in care convoys

Several events occurred in participants' lives which brought changes in their care convoys. These changes had consequences for the structure as well as the function and adequacy of care convoys. Some events caused almost immediate changes in the care convoys (e.g. not allowed to drive anymore) while others generated gradual changes (e.g. physical deterioration). Some events also caused temporary changes (e.g. surgery) while other events created lasting changes (e.g. illness).

Events caused care convoys to change in terms of sufficiency. Participants for example explained how their care convoys grew as existing caregivers provided more intensive care and/or new caregivers appeared in the care convoys. One 81-year old widow explained how her physical deterioration caused more intensive care: 'The doctor needs to come more often. I take more expensive medication. That was not the case before. Now I also have to pay a cleaning lady'. Sometimes care convoys became smaller. One participant indicated that her friends did not help her anymore due to their own personal circumstances such as physical deterioration or the arrival of grandchildren: 'I used to have friends. They helped me with the grocery shopping. One doesn't come anymore because of the travel distance. She is suffering from Multi Sclerosis. And she looks after her grandchildren. And another friend also has a grandchild now and she looks after him every day' (woman, 69 years, divorced). Certain care activities were taken over by other caregivers. One participant explained her daughter took over the help provided by her husband when he died.

Some events caused changes in satisfaction regarding the care convoys. For example, one participant explained her son moved away, and her other son took over the assistance, however, she is not satisfied with this change at all: 'I regret that he [son] now lives at the coast. The other one is not that affectionate. Back then, he came to visit me once in a while. I miss that now' (woman, 85 years, widowed).

3.5. Outcomes of care convoys

Participants recognised the positive outcomes of their convoys for themselves. They described the need of their care convoy if they wanted to age well in place. With the help of others, they felt in some way autonomous and more in control of their daily lives. An 83-years old married men indicated: 'Alone it would be more difficult. If I had to do everything alone, I might be able to do it, but it wouldn't be like this, it wouldn't be in the wright way'. Care convoys also contributed to the quality of life and life satisfaction of the participants. Following quote expresses how a home care organisation brought happiness: 'I really enjoy the organisation. That is the sun, isn't it? I do not say it for the customers or to make you feel good. No, it is superb, it is a great organisation' (woman, 91 years, widowed). Informal and formal caregivers also contributed to the inclusion of the participants by stimulating them to go outside and to participate in activities. One participant went to the library to join a reading group due to her daughter: 'I go to the library with my walker. I am in a reading group, which is a group where we have to read books. My daughter works at the library and she absolutely wanted me to participate in this group' (woman, 86 years, widowed). Participants were also stimulated by their formal caregivers to go outside. For example, the general practitioner advised one of the participants to go to the local service centre. Several formal care services also organised activities outside the home and provided special transport to pick up older adults. This was of great value for many participants because otherwise they would not have the possibility to participate. As one participant stated: 'Fortunately, they have the 'less mobile central'. Otherwise she would not get here, she is not able to use public transport' (translator for woman, 81 years, widowed).

4. Discussion

This study reports qualitative findings of sixty-five semi-structured interviews with frail, community-dwelling older adults who received at least informal care on their meaning and experiences of their care convoy's structure, function and adequacy, how care convoys change over time and perceived (positive) outcomes for themselves. A secondary analysis using thematic (content) techniques was conducted, including both deductive and inductive coding (Cho & Lee, 2014; Fereday & Muir-Cochrane, 2006; McGraw et al., 2017). By doing this, this study extends Kemp et al. (2013) convoy of care model by exploring the model in frail, community-dwelling older adults.

The interviews revealed a great diversity in the *structure* of care convoys among frail, community-dwelling older adults who indicated to receive assistance from both various informal caregivers (e.g. spouse, children, siblings, friends, neighbours) and various formal caregivers (e.g. general practitioner, home nurse, housecleaner). Besides above-mentioned types of caregivers, older adults also considered other services (e.g. social service centres, assistive means) and local merchants (e.g. pharmacist, hairdresser) as types of professional support. Most informal care was provided by the spouse or children, which had also been demonstrated in previous studies (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011). However, participants also indicated friends and neighbours as informal caregivers. This is relevant as a quantitative study showed that non-kin caregivers contribute significantly to the long-term informal care of frail, older adults (Lapierre & Keating, 2013). Similar with Kemp et al. (2018), some care convoys contained a primary informal caregiver who provided most of the informal care, while other care convoys contained several informal caregivers and shared responsibilities. Informal and formal care often co-occur in frail, older adults as participants explained often receiving formal care in addition to informal care. This finding is in accordance with a quantitative study of Lambotte et al. (2018), suggesting that older adults who combine care from family with care from several types of formal caregivers are more physically, psychologically and environmentally frail. Similar with the study of Gregory, Mackintosh, Kumar and Grech (2017), this interplay was characterised by negotiation between the care recipient, informal and/or formal caregivers. However, in this study, when informal and formal caregivers were in touch, care recipients often felt disconnected from this relationship. In line with previous research (Kogan, Wilber, & Mosqueda, 2016; Santana et al., 2018), also our results underline that care and support would benefit from a person-centred and relationship-based, where an individual's preferences, values and needs are assessed, and where all parties are involved in the care process.

Diversity is not only present in the structure of care convoys but also in the *function* of care convoys among frail, community-dwelling older adults. Namely the participants of the current study explained caring for themselves, caring for others, receiving care and exchanging care with their (in)formal caregivers. Furthermore, participants' understanding of care and support covered a wide range of activities (e.g. personal care, home care, transportation, social and emotional support). Noteworthy is the importance of social contacts within informal and formal care relationships. Several studies highlight the significance of interpersonal relations between care provider and care receiver, and the 'social' dimension of care (Cooney, Dowling, Gannon, Dempsey, & Murphy, 2014; Dewar & Nolan, 2013; Walsh & Shutes, 2013). Caregiving is not only instrumental but also involves emotional and personal aspects (Ayalon et al., 2013). Participants of the current study valued the social interactions that resulted from the care and support activities and showed personal attachment towards the individuals who cared for them. Some participants indicated not having the possibility to develop a relational continuity (e.g. due to lack of time of caregivers, formal caregivers' shifts) and mentioned this as a reason why they were not completely satisfied with their care. This is in line with previous research that showed that care provided by the same caregiver over a considerable time is important to generate safety, security and trust in older adults (José et al., 2016). The social dimension of care also reflects the complexity of care convoys of frail, older adults as participants experienced different kinds of relationships depending on the specific caregiver. An example of this complexity is participants' desire for social interactions with their formal caregivers such as the housecleaner, this aspect has in many cases more value than the assistance itself. Furthermore, informal caregivers are not necessarily the closest one to the care recipient. In some cases, participants felt more affection for their formal than informal caregivers.

Another important finding within care convoys' function concerns the active involvement of frail, older adults. Participants expressed this active involvement in several ways. In accordance with Kemp et al. (2018), participants indicated to be actively involved in their care convoy by their capacity for self-care. A central element of self-care is decision-making (Lommi, Matarese, Alvaro, Piredda, & De Marinis, 2015). Participants in this study made decisions about the self-care activities they performed and the activities they delegate to others. But participants also showed active involvement in reciprocal relationships or relationships in which older adults were able to exchange with their caregivers. Reciprocity concerned not only actual exchanges between caregiver and care recipient. The idea that one would give assistance if ever needed was seen as a form of reciprocity by the participants. Finally, some participants – while receiving care – also took care of others and thus, were informal caregivers themselves.

Care convoys showed functional differences between informal and formal care. Participants explained how personal care and housecleaning were care tasks mainly delivered by formal caregivers while informal caregivers supported the participants principally in other home care activities (e.g. administration), transportation and socio-emotional support. These results show that informal care and formal care have both their own dynamics, and that some care tasks are more likely to be provided by specific caregivers. According to Hoefman, Meulenkamp and De Jong (2017), people believe that governments are more responsible for personal and nursing care activities like bathing or dressing and wound care, while informal caregivers hold more responsibility for social needs and support activities such as support with administration. In the current study, there were also functional differences within informal care. Participants often explained how family members cared more extensively while non-kin caregivers provided less intensive care and support, sometimes for the same care activity. Differences in types of assistance between friends/neighbours and family members exist as friends and neighbours limit their assistance to practical tasks such as assistance with transport and socio-emotional support (RIS MRC CFAS et al., 1998). An explanation could be in the nature of the relationship, resulting in differences in motivation to provide assistance: the motivation for family caring is often based on obligation and duty (Finch & Mason, 1993). This does not apply to the same extent with non-relatives (Atkin, 1992).

In accordance with Morrow-Howell, Proctor and Dore (1998), frail, older adults in the current study expressed the *adequacy* of their care convoys in terms of satisfaction and sufficiency. Satisfaction refers to the qualitative dimension of adequacy, sufficiency refers to the quantitative dimension (Morrow-Howell et al., 1998). Both dimensions are not necessarily related to each other as the participants of this study who were satisfied with the care received did not necessarily receive sufficient help, or vice versa. An important aspect related to frail, older adults' satisfaction of their care convoys was being treated with respect and commitment. This is in line with José et al. (2016) suggesting that having respectful and attentive carers is an aspect of good care. Those carers respect the preferences and wishes of older adults, treat them as capable persons, and support and simulate them to make their own choices. With regard to both the quantitative and qualitative component of adequacy, proximity and time played an important role. Regarding proximity, the current study showed similar findings than a study from Broese van Groenou and De Boer (2016) as participants explained that living nearby their informal caregivers was an advantage as it made them feel more secure. In line with Mello et al. (2017), participants in the current study indicated informal caregivers' lack of time because they often had additional roles to fulfil and were in some cases overburden. Older adults tried to cope with this by asking other caregivers for help.

In line with a longitudinal quantitative study from Geerlings, Pot, Twisk and Deeg (2005), this study demonstrates that care convoys are dynamic and change over time. This study provide evidence that changes are not only inherent to the structure of care convoys, but also to their function and adequacy. Participants indicated various changes which made their care convoy's structure, function and adequacy to change (temporarily or permanently). Some events were associated to the wellbeing and health of the participants, other events were inherent to informal caregivers' life.

Finally, care convoys had several (positive) outcomes for frail, community-dwelling older adults. Like in other studies focussing on care and support (e.g. Kadowaki, Wister, & Chappell, 2015; Lloyd, Kendall, Starr, & Murray, 2016; Stones & Gullifer, 2016), care convoys contributed to the participants' life satisfaction, quality of life and ageing in place. In addition, the participants in this study also described their care convoy's importance for inclusion and participation in the community.

4.1. Strengths and limitations

Several limitations need to be acknowledged. First, there may have been inconsistencies between the interviews since several authors conducted the interviews. In order to extend the reliability of the interviews, the interviewers received training before conducting the interviews (Boeije, 2010). This training included: 1) explanation and discussion of the study protocol, 2) explanation and exercises on administering the MoCA (led by a psychologist), 3) debriefing regarding the instructions for the translated questionnaires, and 4) practice conducting the interviews with simulated patients while being recorded. Several scenarios were also developed to address potential difficulties and all interviewers received a list of definitions explaining the terms used in the questionnaire, which could be used if necessary during the interviews. Second, this study performed a secondary analysis. The interviews were conducted to answer a broader range of research questions related to frailty and care and support in later life (Johnston, 2014). Due to this, the original data was not collected to answer the present research questions. In order to overcome this limitation, the investigators explored how well the data corresponded with the research questions by assessing the quality of the data through pre-analyses and discussion as previously recommended by Johnston (2014). Also, the investigators were very well informed and closely associated with the data collection process given their involvement in the overall study (Johnston, 2014).

Despite these limitations, this study has a number of strengths. In order to ensure the trustworthiness of the findings, the co-authors of this study engaged with other researchers to reduce research bias by presenting and discussing preliminary results of the study (Noble & Smith, 2015). In order to enhance the credibility of the findings, the themes were subject of discussion with the team members, and several extracts from various interviews are provided to illustrate the findings (Noble & Smith, 2015).

4.2. Recommendations for future research, policy and practice

With regard to future research, (in)formal caregivers should be involved in the exploration of care convoys as well. Namely studies involving caregivers' voices indicate the existence of discrepancies between the perceptions of the various actors (Brimblecombe, Pickard, King, & Knapp, 2017; Turcotte et al., 2015).

With regard to policy and practice, this study support Wiles (2011) critiques of ageist views, which assume older care recipients to be unproductive and dependent of others. In line with several scholars (e.g. Tronto, 1993; Wiles, 2003), this study acknowledges the need for reconceptualising care as relationships of interdependence between complex networks of actors in various contexts. As Fine and Glendinning (2005) point out, both care recipients and care providers are involved in the co-production of care, wherein different types of care and support are exchanged.

5. Conclusion

In the context of community care, frail, community-dwelling older adults are likely to receive care and support from a diverse range of informal and formal caregivers. This study explores the meaning and experiences of frail, older adults' care convoy (i.e. structure, function and adequacy of care convoys, how care convoys change over time and perceived (positive) outcomes for themselves). The interviews revealed a great diversity in the structure of care convoys as participants indicated to receive assistance from both various informal and formal caregivers. Diversity is also present in the function of care convoys as participants explained caring for themselves, caring for others, receiving care and exchanging care with their (in)formal caregivers. Participants exerted active involvement within their care convoy and valued to social and relational aspect of care. Participants' understanding of care and support covered a wide range of activities, with some activities being more likely to be provided by specific types of caregivers. Participants expressed the adequacy of their care convoys in terms of satisfaction and sufficiency. Noteworthy, one does not necessarily lead to the other as participants who were satisfied with the care received did not necessarily receive sufficient help, or vice versa. Care convoys are dynamic and change over time. These changes are not only inherent to the structure of care convoys, but also to their function and adequacy. Participants in this study described their care convoy's importance for sense of mastery, quality of life, life satisfaction, inclusion and ageing well in place. (Health) care practice and policies should acknowledge the relational and social aspect of care, the complex interplay between care recipients, informal and formal caregivers, and the dynamicity of care convoys of frail, community-dwelling older adults.

References

Agree, E. M., & Glaser, K. (2009). Demography of informal caregiving. In P. Uhlenberg (Ed.), *International handbook of population aging* (pp. 647-668). New York: Springer.

Allen, S. M., & Ciambrone, D. (2003). Community care for people with disability: Blurring boundaries between formal and informal caregivers. *Qualitative Health Research*, *13*(2), 207–226. doi: 10.1177/1049732302239599

Atkin, K. (1992). Similarities and differences between informal carers. In J. Twigg (Ed.), *Carers: Research and practice* (pp. 30-58). London: HMSO.

Ayalon, L., Halevy-Levin, S., Ben-Yizhak, Z., & Friedman, G. (2013). Family caregiving at the intersection of private care by migrant home care workers and public care by nursing staff. *International Psychogeriatrics*, *25*(9), 1463-1473. doi: 10.1017/S1041610213000628

Ayalon, L., & Roziner, I. (2016). Satisfaction with the relationship from the perspectives of family caregivers, older adults and their home care workers. *Aging & Mental Health*, *20*(1), 56-64. doi: 10.1080/13607863.2015.1020412

Blumer, H. (1969). *Symbolic interaction: Perspective and method*. Englewood Cliffs: Prentice Hall.

Boeije, H. (2010). *Analysis in qualitative research*. London: Sage Publications Ltd.

Broese van Groenou, M. I., & De Boer, A. (2016). Providing informal care in a changing society. *European Journal of Ageing*, *13*(3), 271-279. doi: 10.1007/s10433-016-0370-7

Broese van Groenou, M., Jacobs, M., Zwart-Olde, I., & Deeg, D. J. H. (2016). Mixed care network of community-dwelling older adults with physical health impairments in the Netherlands. *Health and Social Care in the Community*, *24*(1), 95-104. doi: 10.1111/hsc.12199

Brimblecombe, N., Pickard, L., King, D., & Knapp, M. (2017). Perceptions of unmet needs for community social care services in England. A comparison of working carers and the people they care for. *Health and Social Care in the Community*, *25*(2), 435-446. doi: 10.1111/hsc.12323

Calasanti, T. (2009). Theorizing feminist gerontology, sexuality, and beyond: An intersectional approach. IN V. L. Bengtson, M. Silverstein, M. M. Putney, & M. Gans (Eds.), *Handbook of theories of aging* (pp. 471-485). New York: Springer.

Cantor, M. (1991). Family and community: Changing roles in an aging society. *The Gerontologist*, *31*(3), 337-346. doi: 10.1093/geront/31.3.337

Chappell, N., & Blandford, A. (1991). Informal and formal care: Exploring the complementarity. *Ageing & Society*, *11*(3), 299-317. doi: 10.1017/S0144686X00004189

Cho, J. Y., & Lee, E.-H. (2014). Reducing confusion about Grounded Theory and Qualitative Content Analysis: Similarities and differences. *The Qualitative Report*, *19*(32), 1-20.

Colombo, F., Llena-Nozal, A., Mercier, J., & Tjadens, F. (2011). *Help Wanted? Providing and Paying for Long-Term Care*. Paris: OECD Publishing.

Cooney, A., Dowling, M., Gannon, M. E., Dempsey, L., & Murphy, K. (2014). Exploration of the meaning of connectedness for older people in long- term care in context of their quality of life: A review and commentary. *International Journal of Older People Nursing*, *9*(3), 192-199. doi: 10.1111/opn.12017

De Roeck, E. E., Dury, S., De Witte, N., De Donder, L., Bjerke, M., De Deyn, P. P., et al. (2018). CFAI-Plus: Adding Cognitive Frailty as a New Domain to the Comprehensive Frailty Assessment Instrument. *International Journal of Geriatric Psychiatry*, *33*(7), 941-947. doi: 10.1002/gps.4875.

Dewar, B., & Nolan, M. (2013). Caring about caring: developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies*, *50*(9), 1247-1258. doi: 10.1016/j.ijnurstu.2013.01.008.

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Schols, J., et al. (2013). The Comprehensive Frailty Assessment Instrument: Development, validity and reliability. *Geriatric Nursing*, *34*(4), 274-281. doi: 10.1016/j.gerinurse.2013.03.002

Dury, S., De Roeck, E., Duppen, D., Fret, B., Hoeyberghs, L., Lambotte, D., et al. (2017). Identifying frailty risk profiles of home-dwelling older people: focus on sociodemographic and socioeconomic characteristics. *Aging & Mental Health*, *21*(10), 1031-1039. doi: 10.1080/13607863.2016.1193120

Dury, S., Dierckx, E., van der Vorst, A., Van der Elst, M., Fret, B., Duppen, D., et al. (2018). Detecting frail, older adults and identifying their strengths: Results of a mixed-methods study. *BMC Public Health*, *18*, 191. doi: 10.1186/s12889-018-5088-3

Elder, G. H. Jr. (1998). The life course and human development. In R. M. Lerner (Ed.), *Handbook of child psychology: Theoretical models of human development* (pp. 939-991). New York: Wiley and Sons.

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, *5*(1), 80-92. doi: 10.1177/160940690600500107

Finch, J., & Mason, J. (1993). *Negotiating Family Responsibilities*. London: Tavistock/Routledge.

Fine, M., & Glendinning, C. (2005). Dependence, independence, or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing & Society*, *25*(4), 602–621. doi: 10.1017/S0144686X05003600

Flemish Government. (2015). *Vlaams Ouderenbeleidsplan 2015-2020*. Retrieved on 27 September 2018, from https://www.vlaanderen.be/en/nbwa-news-message-document/document/09013557801b11b5

Geerlings, S. W., Pot, A. M., Twisk, J. W. R., & Deeg, D. J. H. (2005). Predicting transitions in the use of informal and professional care by older adults. *Ageing & Society*, *25*(1), 111-130. doi: 10.1017/S0144686X04002740

Greene, V. L. (1983). Substitution between formally and informally provided care for the impaired elderly in the community. *Medical Care*, *21*(6), 609-619.

Gregory, A., Mackintosh, S., Kumar, S., & Grech, C. (2017). Experiences of health care for older people who need support to live at home: A systematic review of the qualitative literature. *Geriatric Nursing*, *38*(4), 315-324. doi: 10.1016/j.gerinurse.2016.12.001

Grenier, A. (2007). Constructions of frailty in the English language, care practice and the lived experience. *Ageing & Society*, *27*(3), 425-445. doi: 10.1017/S0144686X06005782

Hoefman, R. J., Meulenkamp, T. M., & De Jong, J. D. (2017). Who is responsible for providing care? Investigating the role of care tasks and past experiences in a cross-sectional survey in the Netherlands. *BMC Health Services Research*, *17*, 477. doi: 10.1186/s12913-017-2435-5

Jacobs, M. T., Broese van Groenou, M. I., Aartsen, M. J., & Deeg, D. J. H. (2018). Diversity in older adults' care networks: The added value of individual beliefs and social network proximity. *Journals of Gerontology: Series B*, *73*(2), 326-336. doi: 10.1093/geronb/gbw012

Jacobs, M., Van Tilburg, T., Groenewegen, P., & Broese van Groenou, M. (2016). Linkages between informal and formal care- givers in home-care networks of frail older adults. *Ageing & Society*, *36*(8). doi: 10.1017/S0144686X15000598

Johnston, M. P. (2014). Secondary data analysis: A method of which time has come. *Qualitative and Quantitative Methods in Libraries*, *3*(3), 619-626.

José, J. d. S., Barros, R., Samitca, S., & Teixeira, A. (2016). Older persons' experiences and perspectives of receiving social care: A systematic review of the qualitative literature. *Health and Social Care in the Community*, *24*(1), 1-11. doi: 10.1111/hsc.12186

Kadowaki, L., Wister, A. V., & Chappell, N. L. (2015). Influence of home care on life satisfaction, loneliness, and perceived life stress. *Canadian Journal on Aging*, *34*(1), 75-89. doi: 10.1017/S0714980814000488

Kahn, R. L., & Antonucci, T. C. (1980). Convoys over the life course: A life course approach. In P. B. Baltes & O. Brim (Eds.), *Life Span development and behavior* (pp. 253-286). New York: Academic Press.

Keating, N., Otfinowski, P., Wenger, C., Fast, J., & Derksen, L. (2003). Understanding the caring capacity of informal networks of frail seniors: A case for care networks. *Ageing & Society*, *23*(1), 115-127. doi: 10.1017/S0144686X02008954

Kemp, C. L., Ball, M. M., Morgan, J. C., Doyle, P. J., Burgess, E. O., Dillard, J. A., … Perkins, M. M. (2017). Exposing the Backstage: Critical Reflections on a Longitudinal Qualitative Study of Residents' Care Networks in Assisted Living. *Qualitative Health Research*, *27*(8), 1190-1202. doi: 10.1177/1049732316668817

Kemp, C. L., Ball, M. M., Morgan, J. C., Doyle, P. J., Burgess, E. O., & Perkins, M. M. (2018). Maneuvering together, apart, and at odds: Residents' care convoys in assisted living. *Journals of Gerontology: Social Sciences*, *73*(4), e13-e23. doi: 10.1093/geronb/gbx184

Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: Theorizing intersections between formal and informal care. *Journal of Aging Studies*, *27*(1), 15-29. doi: 10.1016/j.jaging.2012.10.002

Kogan, A. C., Wilber, K., & Mosqueda, L. (2016). Person-centered care for older adults with chronic conditions and functional impairment: A systematic literature review. *Journal of the American Geriatrics Society*, *64*(1), e1-e7. doi: 10.1111/jgs.13873

Lambotte, D., De Donder, L., Van Regenmortel, S., Fret, B., Dury, S., Smetcoren, A.-S., et al. (2018). Frailty differences in older adults' use of informal and formal care. *Archives of Gerontology and Geriatrics*, *79*, 69-77. doi: 10.1016/j.archger.2018.05.018

Lapierre, T. A., & Keating, N. (2013). Characteristics and contributions of non-kin carers of older people: a closer look at friends and neighbours. *Ageing & Society*, *33*(8), 1442-1468. doi: 10.1017/S0144686X12000736

Litwak, E. (1985). *Helping the elderly: The complementary roles of informal networks and formal systems. Perspectives on Marriage and the Family*. New York: Guilford Press.

Lommi, M., Matarese, M., Alvaro, R., Piredda, M., & De Marinis, M. G. (2015). The experiences of self-care in community-dwelling older people: A meta-synthesis. *International Journal of Nursing Studies*, *52*(12), 1854-1867. doi: 10.1016/j.ijnurstu.2015.06.012.

Lloyd, A., Kendall, M., Starr, J. M., & Murray, S. A. (2016). Physical, social, psychological and existential trajectories of loss and adaptation towards the end of life for older people living with frailty: a serial interview study. *BMC Geriatrics*, *16*,176. doi: 10.1186/s12877-016-0350-y

Means, R., Richards, S., & Smith, R. (2008). *Community care. Policy and practice (4th ed.)*. New York: Palgrave Macmillan.

McGraw, S., Qian, Y., Henne, J., Jarecki, J., Hobby, K., & Yeh, W.-S. (2017). A qualitative study of perceptions of meaningful change in spinal muscular atrophy. *BMC Neurology*, *17*, 68. doi: 10.1186/s12883-017-0853-y

Mello, J. d. A., Van Durme, J. M. T., Cès, S., Spruytte, N., Van Audenhove, C., & Declercq, A. (2017). The determinants of informal caregivers' burden in the care of frail older persons: a dynamic and role-related perspective. *Aging & Mental Health*, *21*(8), 838-843. doi: 10.1080/13607863.2016.1168360

Moos, R. H. (1979). Social ecological perspectives on health. In G. C. Stone, F. Coeh & N. E. Adler (Eds.), *Health psychology, A handbook* (pp. 523-547). San Francisco: Jossey-Bass.

Morrow-Howell, N., Proctor, E. K., & Dore, P. (1998). Adequacy of care: The concept and its measurement. *Research on Social Work Practice*, *8*(1), 86-102. doi: 10.1177/104973159800800107

Nasreddine, Z. S., Phillips, N. A., Bedirian, V., Charbonneau, S., Whitehead, V., & Collin, I., et al. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening tool for Mild Cognitive Impairment. *Journal of the American Geriatrics Society*, *53*(4), 695-699. doi: 10.1111/j.1532-5415.2005.53221.x

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-Based Nursing*, *18*(2), 34-35. doi: 10.1136/eb-2015-102054

Oliveira, M., Bitencourt, C., Teixeira, E., & Santos, A. C. (2013). Thematic content analysis: Is there a difference between the support provided by the MAXQDA® and NVivo® software packages. In A. Mesquita & I. Ramos (Eds.), *Proceedings of the 12th European Conference on Research Methodology for Business and Management Studies* (pp. 304-314).

Porter, E. J. (2005). Older widows' experience of home care. *Nursing Research*, *54*(5), 296-303.

RIS MRC CFAS, Blamford, C., Gregson, B., Farrow, G., Buck, D., Dowswell, T., et al. (1998). Mental and physical frailty in older people: The costs and benefits of informal care. *Ageing & Society*, *18*(3), 317-354.

Santana, M. J., Manalili, K., Jolley, R. J., Zelinsky, S., Quan, H., & Lu, M. (2018). How to practice person-centred care: A conceptual framework. *Health Expectations*, *21*(2), 429-440. doi: 10.1111/hex.12640

Smetcoren, A.-S. (2015). *'I'm not leaving!?' Critical perspectives on 'ageing in place'*.

Stones, D., & Gullifer, J. (2016). 'At home it's just so much easier to be yourself': Older adults' perceptions of ageing in place. *Ageing & Society*, *36*(3), 449-481. doi: 10.1017/S01444686X14001214

Turcotte, P.-L., Larivière, N., Desrosiers, J., Voyer, P., Champoux, N., Carbonneau, H., et al. (2015). Participation needs of older adults having disabilities and receiving home care: met needs mainly concern daily activities, while unmet needs mostly involve social activities. *BMC Geriatrics*, *15*, 95. doi: 10.1186/s12877-015-0077-1

Tronto, J. (1993). *Moral Boundaries: A Political Argument for an Ethic of Care*. New York: Routledge.

Vandeurzen, J. (2016). *Nabije zorg in een warm Vlaanderen. Vlaams Mantelzorgplan 2016–2020.* Retrieved on 27 September 2018, from https://www.vlaanderen.be/nl/publicaties/detail/nabij-zorg-in-een-warm-vlaanderen-vlaams-mantelzorgplan-2016-2020

Verver, D., Merten, H., Robben, P., & Wagner, C. (2018). Care and support for older adults in the Netherlands living independently. *Health & Social Care in the Community*, *26*(3), e404-e414. doi: 10.1111/hsc.12539

Ward-Griffin, C., & Marshall, V. W. (2003). Reconceptualizing the relationship between "public" and "private" eldercare. *Journal of Aging Studies*, *17*(2), 189-208. doi: 10.1016/S0890-4065(03)00004-5

Walsh, K., & Shutes, I. (2013). Care relationships, quality of care and migrant workers caring for older people. *Ageing & Society*, *33*(3), 393-420. doi: 10.1017/S0144686X11001309

Wiles, J. L. (2003) Daily geographies of caregivers: mobility, routine, scale. *Social Science & Medicine*, *57*(7), 1307–1325. doi: 10.1016/S0277-9536(02)00508-7

Wiles, J. (2011). Reflections on being a recipient of care: Vexing the concept of vulnerability. *Social & Cultural Geography*, *12*(6), 573-588. doi: 10.1080/14649365.2011.601237

Chapter 8. Frailty and wellbeing in community-dwelling older adults: The moderating role of care convoys

Manuscript submitted

Lambotte, D., Dury, S., Dierckx, E., Kardol, M. J. M., De Donder, L, & the D-SCOPE Consortium. Frailty and wellbeing in community-dwelling older adults: The moderating role of care convoys.

Abstract

Research has pointed towards the dynamic state of frailty and indicated that frail, older adults' strengths and resources can decrease negative experiences of frailty and increase positive outcomes. Based on the convoy of care model, this study explores the moderating role of care convoy properties (i.e. structure, function and adequacy) between multidimensional frailty and wellbeing outcomes in community-dwelling older adults. Moderation analyses were performed among 619 older care recipients (60+) at risk for frailty in Flanders, Belgium. The results indicate that receiving care from non-kin caregivers and care convoys' adequacy (containing sufficiency and satisfaction of care convoys) are important positive 'balancing' factors for the relationship between frailty and wellbeing in older adults. Practitioners and policy makers would benefit from recognizing the multidimensionality of frailty in older adults as well as the complexity of care convoys and their potential role in balancing frailty.

Keywords

Frailty; wellbeing; care convoys; frailty balance; moderation; PROCESS tool

1. Introduction

European countries are confronted with an increasing population of older adults and age-related chronic diseases such as dementia and cardiovascular diseases (Prince et al., 2015). Within this ageing population, many older adults become frail and in need of care and support (Lambotte et al., 2018a). Frailty in old age increases the risk for adverse outcomes such as hospitalisation and institutionalisation (Vermeiren et al., 2016). Governments are searching for solutions to reduce (the high costs of) adverse outcomes, and ways how to support deinstitutionalisation (Dury, 2018; Means, Richards, & Smith, 2008). Connected to this 'ageing in place-policy discourse', the greater part of frail, community-dwelling older adults receive assistance from formal home care services as well as from professionals and informal caregivers (Geerts & Van den Bosch, 2012).

The prevalence of frailty strongly depends on its conceptualisation and population included. A systematic review concluded that the prevalence of frailty ranges from 4.0% to 59.1% (Collard, Boter, Schoevers, & Oude Voshaar, 2012). Frailty has often been operationalised as a physical construct. However, a growing number of studies have approached frailty as a multidimensional concept, which considers the complex interplay between physical, cognitive, psychological, social and environmental factors (De Witte et al., 2013; Khezrian, Myint, McNeil, & Murray, 2017). Moreover, not only researchers identify frailty in a multidimensional way, older adults themselves experience frailty as more than only a physical issue as well (Dury et al., 2018; Grenier, 2007).

In general, studies point towards the negative relationship between frailty and several domains of wellbeing like life satisfaction, meaning in life, sense of mastery and quality of life (Elliot, Mooney, Infurna, & Chapman, 2018; Gobbens & van Assen, 2014; Kojima, Iliffe, Jivraj, & Walters, 2016; Zhang et al., 2018). Although frailty is often interpreted as a negative construct, studies point towards the dynamic state of frailty and use the term 'frailty balance' (Dury et al., 2018; Gobbens, Schols, & van Assen, 2017). Namely frail, older adults can still report high levels of wellbeing despite their deficits (Ament, de Vugt, Verhey, & Kempen, 2014; Andreasen, Lund, Aadahl, Gobbens, Sorensen, 2015). Frail, older adults' strengths and resources (cf. balancing factors) can decrease negative experiences of frailty and increase positive outcomes (Dury et al., 2018; van der Vorst et al., 2017). Within this frailty balance, informal and formal care may be of great importance. For example, Dury et al. (2018) suggest that (in)formal care and experiencing good quality of care are important for a good quality of life in frail, older adults.

As for research on informal and formal care, several authors have underlined the importance to step away from a dyadic perspective for informal and formal care and have argued to approach informal and formal care from a network perspective (Jacobs, Van Tilburg, Groenewegen, & Broese van Groenou, 2016; Koehly, Ashida, Schafer, & Ludden, 2015). Within this perspective, Kemp, Ball and Perkins (2013) introduced a comprehensive approach on care relationships: "the convoy of care model". This model suggests that frail, older adults are situated within care convoys, defined as "*the evolving collection of individuals who may or may not have close personal connections to the recipient or to one another, but who provide care, including help with activities of daily living (IADLs), socio-emotional care, skilled health care, monitoring and advocacy*" (Kemp et al., 2013, p. 18). According to Kemp et al. (2013) each individual's care convoy has properties unique in structure (e.g. composition of care convoys) and function (e.g. type of support given, received, exchanged), both of which can influence its adequacy (e.g. quality of care convoys). With regard to the *structure* of care convoys, research demonstrated the diversity in types of (in)formal caregivers and care networks of frail, older adults (e.g. Jacobs; Broese van Groenou, Aartsen, & Deeg, 2018; Lambotte et al., 2018a). Concerning the *function* of care convoys, studies provide evidence on the various care needs of frail, older adults: physical needs, like personal care and medication use; psychosocial needs, like social support and company; and environmental needs, like transportation (Fret et al., 2017; Hoogendijk et al., 2014). Finally, care convoys' *adequacy* regards the quality of care convoys. Current research suggests a difference between two dimensions, satisfaction and sufficiency, and indicate that although older adults are often satisfied with the care received, this does not necessarily mean the care provision is sufficient (McCann & Evans, 2002; Morrow-Howell, Proctor, & Dore, 1998).

According to Kemp et al. (2013) care convoys have outcomes for self and identity, which are intimately connected to care recipients' ability to age in place and wellbeing.

To our knowledge, until now, the convoy of care model has only been explored in the context of assisted living (Kemp et al., 2013, 2017, 2018). Therefore, the purpose of this study is to examine if and how care convoy properties (i.e. structure, function and adequacy of care convoys) might moderate the relationship between multidimensional frailty (i.e. physical, cognitive psychological, social and environmental frailty) and wellbeing outcomes (i.e. mastery, meaning in life and life satisfaction) among community-dwelling older adults. These 'positive' outcomes are proven to be important components of wellbeing in (frail) older adults (Battersby & Phillips, 2016; Dent & Hoogendijk, 2014; Dury et al., 2008; Lee et al., 2016; Wilhelmson et al., 2013).

2. Methods

2.1. Study design

The cross-sectional data for this study originates from the Detection, Support and Care for older people, Prevention and Empowerment (D-SCOPE) frailty program (see Lambotte et al., 2018 for a full description). The D-SCOPE frailty program is a longitudinal research study (2017-2018) which through a Randomized Controlled Trial (RCT), aimed to evaluate a detection and prevention program on frailty among 900 community-dwelling older adults (60+) at risk for frailty. The study was conducted in three municipalities in Flanders (Belgium): one coastal town (Knokke-Heist), one medium-sized town (Tienen) and one city (Ghent). In each municipality, 300 addresses and replacement addresses from older adults were randomly selected from the census records, based on risk profiles for frailty (Dury et al., 2017). If potential participants were willing to participate, trained older volunteers or researchers informed the participants in person about the study. Participants received the opportunity to ask questions as well. The trained older volunteers or researchers conducted the baseline assessment (T0) face-to-face after the informed consent had been signed by the participant. The same older volunteers or researchers conducted the T1 study assessment, 6 months after T0. The baseline assessment (as well as the T1 study assessment) consisted of a survey including questions on socio-demographic and socio-economic characteristics, multidimensional frailty (i.e. physical, cognitive, psychological, social and environmental frailty), frailty-balance (e.g. informal and formal care, neighbourhood, coping) and positive outcomes (e.g. meaning in life, sense of mastery, life satisfaction). Both assessments were conducted in the home of the participants.

The D-SCOPE frailty program has been reviewed and approved by the medical ethics committee of the Vrije Universiteit Brussel, Brussels, Belgium (reference number: B.U.N. 143,201,630,458).

The current paper only uses T0 the data of the baseline assessment (T0), which was conducted from June 2017 to October 2017. This home visit lasted on average 67.46 minutes (SD = 28.6), ranging from 20 minutes to 360 minutes.

2.2. Measurements

Multidimensional frailty

Multidimensional frailty in older adults was measured using the Comprehensive Frailty Assessment Instrument Plus (CFAI-Plus; De Roeck et al., 2018). The CFAI-plus is an extended version of the CFAI (De Witte et al., 2013), a self-assessment instrument which measures 5 domains of frailty: physical, cognitive, psychological, social and environmental frailty. *Physical frailty* assesses the general physical health with four items (e.g. walking up a hill or stairs). *Psychological frailty* measures mood-disorders and emotional loneliness with eight items (e.g. losing self-confidence). *Social frailty* assesses social loneliness with three items (e.g. there are enough people I feel close to) and social support network with ten items (e.g. children, neighbours). *Environmental frailty* measures housing conditions with five items (e.g. my house is not comfortable). The CFAI was validated among 33,629 community-dwelling older adults, using a second-order confirmatory factor analysis (De Witte et al., 2013).

Cognitive frailty has been added to the CFAI, resulting in the CFAI-Plus (De Roeck et al., 2018). Cognitive frailty assesses subjective cognitive complaints with four items (e.g. I have trouble with remembering things that have happened recently).

In the present study, items for the five frailty subdomains showed internal consistency with Cronbach's α reliability scores of .820 for physical frailty, .706 for cognitive frailty, .849 for psychological frailty, .710 for social frailty and .628 for environmental frailty.

Positive outcomes of wellbeing

Sense of mastery is measured by a questionnaire which evaluates to what extent people feel they exert control over existing circumstances of their lives with four items (e.g. I often feel helpless in dealing with problems of life) (Pearlin, Nguyen, Schieman, & Milkie, 2007). One self-constructed question was added to assess mastery in relation to others (Verkerk, 2001). *Life satisfaction* is measured by using the Satisfaction with Life Scale, a validated scale which focusses on global life satisfaction with five items (e.g. I am satisfied with my life) (Diener, Emmons, Larsen, & Griffin, 1985). *Meaning in life* is assessed by the use of the Meaning in Life Questionnaire (MLQ) and measures perceived meaning in life with five items (e.g. I understand my life's meaning) (Steger, Frazier, Oishi, & Kaler, 2006). Participants rated each item on a 5-point scale from 1 (totally disagree) to 5 (totally agree).

In the present study, items for the three wellbeing subdomains showed internal consistency with Cronbach's α reliability scores of .779 for sense of mastery, .870 for life satisfaction and .815 for meaning in life.

Properties of care convoys

For the *structure* of care convoys (i.e. composition of care convoys), several types of caregivers were used. 7 categories of caregivers were made by combining two questions from the D-SCOPE questionnaire. 4 of the 7 categories referred to informal care: (1) nuclear family (partner and/or children); (2) extended family (grandchildren and/or other relatives); (3) friends/acquaintances; and (4) neighbours. The other 3 categories referred to formal care: (1) general practitioner; (2) home nursing; and (3) formal home assistance (senior companion care, services for home care, cleaning services, grocery services, chores services, hot meals and/or day care/short term care). The first question asked to the participants from whom they received assistance (21 potential persons or organisations). The second question asked the participants how many times they consulted a general practitioner during the last six months. Receiving assistance from the general practitioner was defined as consulting at least on time a general practitioner during the last six months.

The *function* of care convoys (i.e type of support given) was measured by the question whether respondents needed help with 8 activities of daily life: personal care, household tasks, personal displacements, administration and financial management, social company and support, grocery shopping, chores and supervision.

For the *adequacy* of care convoys (i.e. quality of care convoys), we used sufficiency with the help received for abovementioned 8 activities; and satisfaction with the informal and/or formal care received.

Control variables

We included several socio-demographic and socio-economic characteristics as control variables in the analyses (i.e. age, gender, partnership, educational level, household income), as they might influence multidimensional frailty (Dury et al., 2017).

2.3. Study population

The original T0 data sample consisted of 869 community-dwelling older adults at risk for frailty. 34.4% participants lived in Ghent (N = 299), 33.7% in Knokke-Heist (N = 293) and 31.9% in Tienen (N = 277).

The analyses of this study are performed among those older adults who indicated to receive care and thus who were embedded in a care convoy (N = 619). Table 10 provides the descriptive statistics of the main variables, percentages, mean scores and standard deviation. The mean age of the participants included in the present study was 77 years, with the majority being female (53.2%) and having no partner (63.3%).

Table 10. Descriptive statistics of the study variable (N = 619).

Study variables		**N (valid %)**	**Mean (S.D.)**	**Range**
Control variables				
Gender	Male	290 (46.8)		
	Female	329 (53.2)		
Age			76.79 (8.02)	59 - 95
Partnership	No partner	392 (63.3)		
	Has partner	225 (36.3)		
Educational level	No degree obtained	13 (2.1)		
	Primary education	40 (6.5)		
	Lower secondary education	201 (32.7)		
	Higher secondary education	213 (34.7)		
	Higher of university education	147 (23.9)		
Household income	Between € 500 and € 999	21 (3.9)		
	Between € 1,000 and € 1,250	139 (25.7)		
	Between € 1,251 and € 1,499	114 (21.1)		
	Between € 1,500 and € 1,999	111 (20.5)		
	Between € 2,000 and € 2,499	80 (14.8)		
	> € 2,500	76 (14)		
Structure of care convoys: receiving care from				
Nuclear family		382 (61.8)		
Extended family		175 (28.3)		
Friends/acquaintances		122 (19.7)		
Neighbours		128 (20.7)		
General practitioner		564 (91.1)		
Home nursing		112 (18.1)		
Formal home assistance		355 (57.4)		
Function of care convoys: needing assistance for				
Personal care		114 (18.8)		
Household tasks		329 (54.3)		
Personal displacements		170 (28.1)		
Administration and financial management		199 (33.3)		
Social company and support		93 (15.4)		
Grocery shopping		240 (39.6)		
Chores		320 (53.3)		
Supervision		19 (3.2)		
Adequacy: quality of care convoys, sufficient help with				
Personal care		97 (91.5)		
Household tasks		273 (86.7)		
Personal displacements		138 (86.8)		
Administration and financial management		180 (94.2)		
Social company and support		43 (55.1)		
Grocery shopping		212 (93)		
Chores		253 (83.5)		
Adequacy: quality of care convoys, satisfaction with				
Informal care		509 (96.4)		
Formal care		505 (94.4)		
Independent variables (predictors)				
Physical frailty			39.45 (38.00)	0 - 100
Cognitive frailty			25.99 (24.8)	0 - 100
Psychological frailty			21.26 (22.45)	0 - 100
Social frailty			47.95 (19.67)	0 - 100
Environmental frailty			11.85 (16.06)	0 - 100
Dependent variables (outcomes)				
Sense of mastery			19.59 (4.74)	5 - 25
Meaning in life			18.81 (4.51)	5 - 25

2.4. Statistical analysis

We conducted moderation analyses, which is a type of regression analysis. A moderator variable affects the relationship between a predictor (independent) variable and an outcome (dependent) variable (Field, 2018). In our study we want to explore the impact of multidimensional frailty (i.e. physical, cognitive, psychological, social, and environmental frailty as predictors or independent variables) on the three dependent variables of wellbeing (i.e. sense of mastery, life satisfaction, meaning in life), under the influence of moderators (i.e. care convoys' structure, function and adequacy).

All statistical analyses were performed using the SPSS version 25.0. We conducted SPSS PROCESS macro v2.16.3 for testing hypotheses on the moderation effects (Field, 2018; Hayes, 2013). Significance within the models were reached when $p < .05$. Only the significant moderation effects are reported in the result section.

Each frailty domain (predictor) ranged from 0 to 100, with higher scores indicating being frailer on that particular domain. Each wellbeing domain (outcome) ranged from 5 to 25, with higher scores indicating having a better wellbeing on that particular domain. Care convoy's structure, function and adequacy variables (moderators) are dichotomous variables: types of caregiver whether or not present (structure), whether or not needing care for activities of daily life (function), whether or not being satisfied with (in)formal care (adequacy, satisfaction), and whether or not receiving sufficient care and support for the activities of daily life (adequacy, sufficiency).

3. Results

3.1. Properties of care convoys: structure

Table 11 shows the interaction effects between care convoy's structure and frailty domains on sense of mastery, life satisfaction and meaning in life.

Regarding *physical frailty*, moderation analyses showed a significant interaction effect of physical frailty and receiving assistance from neighbours on life satisfaction (b = 0.027, 95% CI [0.002, 0.051], t = 2.164, p = .031) (Table 11). Looking at the conditional effects, physical frailty was predictive for less life satisfaction for older adults who did not receive assistance from neighbours (b = -0.044, 95% CI [-0.057, -0.031], t = -6.872, p < .001) but was not predictive for older adults who received assistance from neighbours (*b* = -0.017, 95% CI [-0.039, 0.004], *t* = -1.593, *p* = .112).

Regarding *psychological frailty*, moderation analyses demonstrated a significant interaction effect of psychological frailty and receiving assistance from neighbours on life satisfaction (*b* = 0.053, 95% CI [0.009, 0.096], *t* = 2.389, *p* = .017). Looking at the conditional effects, psychological frailty was predictive of less life satisfaction for both older adults who received assistance from neighbours (*b* = -0.047, 95% CI [-0.086, -0.008], *t* = -2.346, *p* = .019) and older adults who did not received assistance from neighbours (*b* = -0.099, 95% CI [-0.121, -0.078], *t* = -9.092, *p* < .001). But the betas showed a significant greater negative relationship for older adults who did not receive assistance from neighbours.

There was also a significant interaction effect of psychological frailty and receiving assistance from friends/acquaintances on meaning in life (*b* = 0.063, 95% CI [0.015, 0.111], *t* = 2.573, *p* = .01). Looking at the conditional effects, psychological frailty was predictive for less meaning in life for older adults who did not receive assistance from friends (*b* = -0.099, 95% CI [-0.118, -0.08], *t* = -10.199, *p* < 0.001) but was not predictive for older adults who received assistance from friends (*b* = -0.036, 95% CI [-0.081, 0.008], *t* = -1.605, *p* = .109).

Regarding *environmental frailty*, moderation analyses showed a significant interaction effect of environmental frailty and receiving assistance from neighbours on sense of mastery (b = 0.075, 95% CI [0.018, 0.133], t = 2.581, p = .01). Looking at the conditional effects, environmental frailty was predictive for less sense of mastery for older adults who did not receive assistance from neighbours (b = -0.078, 95% CI [-0.106, -0.05], t = -5.405, p < .001) but was not predictive for older adults who received assistance from neighbours (b = -0.002, 95% CI [-0.052, 0.048], t = -0.098, p = .922).

Table 11. Interaction effects between care convoy’s structure and frailty domains on sense of mastery, life satisfaction and meaning in life (N = 619)

			Sense of mastery					Life satisfaction					Meaning In life				
			Phys. frailty	Cog. frailty	Psych. frailty	Soc. frailty	Envir. frailty	Phys. frailty	Cog. frailty	Psych. frailty	Soc. frailty	Envir. frailty	Phys. frailty	Cog. frailty	Psych. frailty	Soc. frailty	Envir. frailty
Nuclear family (NF)		R^2	.202*	.199*	.372*	.104*	.076*	.201*	.174*	.283*	.176*	.13*	.115*	.161*	.24*	.155*	.083*
	NF	*B*	0.065	0.634	-0.506	-0.865	-0.16	0.333	0.495	0.214	0.473	0.081	0.992	1.346*	0.432	0.058	0.594
	Frailty	*B*	-0.049*	-0.062*	-0.122*	-0.066*	-0.053*	-0.04*	-0.047*	-0.088*	-0.052*	-0.043*	-0.017	-0.031*	-0.079*	-0.067*	-0.021
	NF*frailty	*B*	**-0.008**	**-0.026**	**-0.005**	**-0.001**	**-0.008**	**0.003**	**0.002**	**0.001**	**-0.015**	**0.024**	**-0.013**	**-0.034**	**-0.01**	**-0.006**	**-0.009**
Extended family (EF)		R^2	.201*	.196*	.368*	.108*	0.078*	.203*	.171*	.285*	.180*	.129*	.113*	.153*	.241*	.159*	.08*
	EF	*B*	0.104	-0.107	0.236	0.315	-0.608	-0.663	-0.04	-0.306	-0.061	-0.347	0.87	0.518	0.262	-0.09	0.141
	Frailty	*B*	-0.052*	-0.077*	-0.121*	-0.059*	-0.069*	-0.043*	-0.044*	-0.096	-0.06*	-0.036*	-0.02*	-0.048*	-0.088*	-0.07*	-0.028
	EF*frailty	*B*	**-0.006**	**-0.007**	**-0.01**	**-0.03**	**0.036**	**0.016**	**-0.002**	**0.023**	**-0.015**	**0.027**	**-0.015**	**-0.018**	**0.005**	**-0.013**	**0.004**
Friends/acq. (FR)		R^2	.203*	.199*	.368*	0.1*	0.078*	.2*	.172*	.284*	.180*	.127*	.114*	.152*	.258*	.155*	.082*
	FR	*B*	-0.573	-0.301	-0.324	0.297	-0.423	-0.465	-0.412	-0.547	0.622	0.25	0.09	-0.164	-0.897	-0.588	0.443
	Frailty	*B*	-0.058*	-0.078*	-0.127*	-0.059*	-0.067*	-0.04*	-0.046*	-0.091*	-0.057*	-0.027	-0.028*	-0.056*	-0.099*	-0.072*	-0.028
	FR*frailty	*B*	**0.016**	**-0.014**	**0.008**	**-0.020**	**0.042**	**0.011**	**0.005**	**0.019**	**-0.03**	**-0.01**	**0.013**	**0.017**	**0.063***	**0.011**	**0.004**
Neighbours (NB)		R^2	.203*	.199*	.371*	.107*	0.089*	.21*	0.175*	.296*	.175*	.131*	.11*	.152*	.251*	.158*	.084*
	NB	*B*	-0.626	-0.835	-0.903	-1.099	-1.426*	-0.451	-0.008	-0.61	-0.226	0.286	0.468	0.499	-0.737	-0.48	-0.264
	Frailty	*B*	-0.054*	-0.082*	-0.13*	-0.068*	-0.078*	-0.044*	-0.049*	-0.099*	-0.06*	-0.036*	-0.023*	-0.051*	-0.098*	-0.073*	-0.037*
	NB*frailty	*B*	**0.002**	**0.008**	**0.023**	**-0.003**	**0.075***	**0.027***	**0.021**	**0.053***	**0.005**	**0.025**	**-0.007**	**-0.012**	**0.048**	**-0.004**	**0.039**
General pract. (GP)		R^2	.208*	.204*	0.368*	.103*	0.082*	0.202*	0.174*	0.283*	0.179*	.132*	.11*	.151*	0.24*	0.156*	0.081*
	GP	*B*	-0.229	-0.915	0.12	-1.347	-0.331	0.273	-1,124	-0.568	-0.68	-1.459*	0.094	-0.342	0.126	-1.863	-0.635
	Frailty	*B*	-0.088*	-0.11*	-0.12*	-0.073*	-0.032	-0.008	-0.069*	-0.1*	-0.054*	-0.074*	-0.012	-0.057*	-0.092*	-0.095*	-0.051
	GP*frailty	*B*	**0.035**	**0.031**	**-0.006**	**0.011**	**-0.032**	**-0.032**	**0.026**	**0.014**	**-0.006**	**0.05**	**-0.013**	**0.004**	**0.007**	**0.028**	**0.026**
Home nursing (HN)		R^2	.212*	.229*	.383*	.14*	.115*	.211*	.181*	.285*	.188*	.14*	.118*	.17*	.247*	.171*	.1*
	HN	*B*	-1.759	-1.889	-1.132	-2.396	-2.718*	-2.745*	-1.495	-0.244	-1.389	-1.428	-0.831	-0.519	-0.097	-0.942	-1.383
	Frailty	*B*	-0.051*	-0.073*	-0.117*	-0.056*	-0.057*	-0.042*	-0.044*	-0.082*	-0.058*	-0.027	-0.02*	-0.044*	-0.077*	-0.064*	-0.019
	HN*frailty	*B*	**0.006**	**-0.012**	**-0.014**	**-0.004**	**0.013**	**0.035**	**0.008**	**-0.013**	**0.000**	**0.000**	**-0.006**	**-0.031**	**-0.026**	**-0.012**	**-0.022**
Formal home ass. (FH)		R^2	.204*	.202*	.368*	.105*	0.086*	.199*	.172*	.283*	.175*	.129*	.114*	.16*	.24*	.161*	.094*
	FH	*B*	-0.481	-0.683	-0.115	-0.063	-1.19*	-0.225	-0.137	0.34	-0.418	-0.535	-0.431	-1.214*	-0.284	0.104	-1.38*
	Frailty	*B*	-0.051*	-0.077*	-0.122*	-0.05*	-0.071*	-0.04*	-0.043*	-0.086*	-0.062*	-0.043*	-0.021*	-0.065*	-0.084*	-0.057*	-0.052
	FH*frailty	*B*	-0.003	-0.004	-0.004	-0.016	0.021	0.004	-0.003	-0.003	0.005	0.024	-0.005	0.02	-0.001	-0.017	0.041

Effects are adjusted for age, gender, partnership, educational level and household income; * $p < .05$

3.2. Properties of care convoys: function

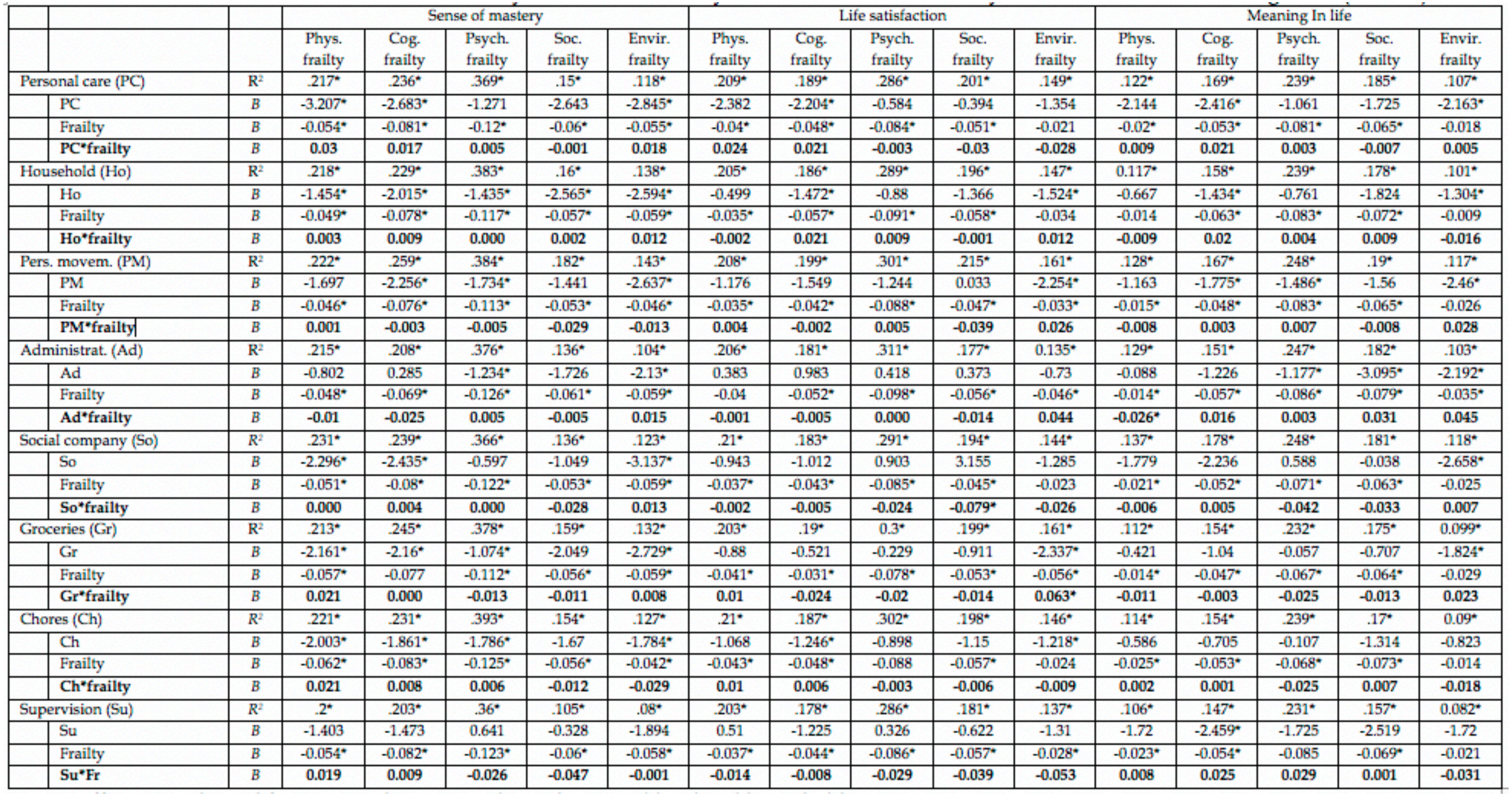
Table 12 provides the interaction effects between care convoy's function and frailty domains on sense of mastery, life satisfaction and meaning in life.

Regarding *physical frailty*, moderation analyses showed a significant interaction effect of physical frailty and needing assistance for administration and financial management on meaning in life (*b* = -0.026, 95% CI [-0.049, -0.003], *t* = -2.19, *p* = .029). Looking at the conditional effects, physical frailty was predictive of less meaning in life for both older adults who needed assistance for administration and financial management (*b* = -0.039, 95% CI [-0.059, -0.02], *t* = -3.963, *p* < .001) and older adults who did not need assistance for administration and financial management (*b* = -0.014, 95% CI [-0.026, -0.001], *t* = -2.115, *p* = .035). But the betas showed a significant greater negative relationship for older adults who needed assistance for administration and financial management.

Regarding *social frailty*, moderation analyses demonstrated a significant interaction effect of social frailty and needing assistance for social company and support on life satisfaction (*b* = -0.079, 95% CI [-0.139, -0.02], *t* = -2.625, *p* = .009). Looking at the conditional effects, social frailty was predictive of less life satisfaction for both older adults who needed social company and support (*b* = -0.125, 95% CI [-0.181, -0.068], *t* = -4.364, *p* < .001) and older adults who did not need social company and support (*b* = -0.045, 95% CI [-0.066, -0.024], *t* = -4.292, *p* < .001). But the betas showed a significant greater negative relationship for older adults who needed social support and company.

Regarding *environmental frailty*, moderation analyses described a significant interaction effect of environmental frailty and needing assistance for grocery shopping on life satisfaction (*b* = 0.063, 95% CI [0.011, 0.115], *t* = 2.389, *p* = .017). Looking at the conditional effects, environmental frailty was predictive of less life satisfaction for older adults who did not need assistance for grocery shopping (*b* = -0.056, 95% CI [-0.086, -0.025], *t* = -3.594, *p* < .001) but was not predictive for older adults who needed assistance for grocery shopping (*b* = 0.007, 95% CI [-0.035, 0.05], *t* = 0.339, *p* = .735).

Table 12. Interaction effects between care convoy's function and frailty domains on sense of mastery, life satisfaction and meaning in life (N = 619)



			Sense of mastery					Life satisfaction					Meaning In life				
			Phys. frailty	Cog. frailty	Psych. frailty	Soc. frailty	Envir. frailty	Phys. frailty	Cog. frailty	Psych. frailty	Soc. frailty	Envir. frailty	Phys. frailty	Cog. frailty	Psych. frailty	Soc. frailty	Envir. frailty
Personal care (PC)		R²	.217*	.236*	.369*	.15*	.118*	.209*	.189*	.286*	.201*	.149*	.122*	.169*	.239*	.185*	.107*
	PC	*B*	-3.207*	-2.683*	-1.271	-2.643	-2.845*	-2.382	-2.204*	-0.584	-0.394	-1.354	-2.144	-2.416*	-1.061	-1.725	-2.163*
	Frailty	*B*	-0.054*	-0.081*	-0.12*	-0.06*	-0.055*	-0.04*	-0.048*	-0.084*	-0.051*	-0.021	-0.02*	-0.053*	-0.081*	-0.065*	-0.018
	PC*frailty	*B*	**0.03**	**0.017**	**0.005**	**-0.001**	**0.018**	**0.024**	**0.021**	**-0.003**	**-0.03**	**-0.028**	**0.009**	**0.021**	**0.003**	**-0.007**	**0.005**
Household (Ho)		R²	.218*	.229*	.383*	.16*	.138*	.205*	.186*	.289*	.196*	.147*	0.117*	.158*	.239*	.178*	.101*
	Ho	*B*	-1.454*	-2.015*	-1.435*	-2.565*	-2.594*	-0.499	-1.472*	-0.88	-1.366	-1.524*	-0.667	-1.434*	-0.761	-1.824	-1.304*
	Frailty	*B*	-0.049*	-0.078*	-0.117*	-0.057*	-0.059*	-0.035*	-0.057*	-0.091*	-0.058*	-0.034	-0.014	-0.063*	-0.083*	-0.072*	-0.009
	Ho*frailty	*B*	**0.003**	**0.009**	**0.000**	**0.002**	**0.012**	**-0.002**	**0.021**	**0.009**	**-0.001**	**0.012**	**-0.009**	**0.02**	**0.004**	**0.009**	**-0.016**
Pers. movem. (PM)		R²	.222*	.259*	.384*	.182*	.143*	.208*	.199*	.301*	.215*	.161*	.128*	.167*	.248*	.19*	.117*
	PM	*B*	-1.697	-2.256*	-1.734*	-1.441	-2.637*	-1.176	-1.549	-1.244	0.033	-2.254*	-1.163	-1.775*	-1.486*	-1.56	-2.46*
	Frailty	*B*	-0.046*	-0.076*	-0.113*	-0.053*	-0.046*	-0.035*	-0.042*	-0.088*	-0.047*	-0.033*	-0.015*	-0.048*	-0.083*	-0.065*	-0.026
	PM*frailty	*B*	**0.001**	**-0.003**	**-0.005**	**-0.029**	**-0.013**	**0.004**	**-0.002**	**0.005**	**-0.039**	**0.026**	**-0.008**	**0.003**	**0.007**	**-0.008**	**0.028**
Administrat. (Ad)		R²	.215*	.208*	.376*	.136*	.104*	.206*	.181*	.311*	.177*	0.135*	.129*	.151*	.247*	.182*	.103*
	Ad	*B*	-0.802	0.285	-1.234*	-1.726	-2.13*	0.383	0.983	0.418	0.373	-0.73	-0.088	-1.226	-1.177*	-3.095*	-2.192*
	Frailty	*B*	-0.048*	-0.069*	-0.126*	-0.061*	-0.059*	-0.04	-0.052*	-0.098*	-0.056*	-0.046*	-0.014*	-0.057*	-0.086*	-0.079*	-0.035*
	Ad*frailty	*B*	**-0.01**	**-0.025**	**0.005**	**-0.005**	**0.015**	**-0.001**	**-0.005**	**0.000**	**-0.014**	**0.044**	**-0.026***	**0.016**	**0.003**	**0.031**	**0.045**
Social company (So)		R²	.231*	.239*	.366*	.136*	.123*	.21*	.183*	.291*	.194*	.144*	.137*	.178*	.248*	.181*	.118*
	So	*B*	-2.296*	-2.435*	-0.597	-1.049	-3.137*	-0.943	-1.012	0.903	3.155	-1.285	-1.779	-2.236	0.588	-0.038	-2.658*
	Frailty	*B*	-0.051*	-0.08*	-0.122*	-0.053*	-0.059*	-0.037*	-0.043*	-0.085*	-0.045*	-0.023	-0.021*	-0.052*	-0.071*	-0.063*	-0.025
	So*frailty	*B*	**0.000**	**0.004**	**0.000**	**-0.028**	**0.013**	**-0.002**	**-0.005**	**-0.024**	**-0.079***	**-0.026**	**-0.006**	**0.005**	**-0.042**	**-0.033**	**0.007**
Groceries (Gr)		R²	.213*	.245*	.378*	.159*	.132*	.203*	.19*	0.3*	.199*	.161*	.112*	.154*	.232*	.175*	0.099*
	Gr	*B*	-2.161*	-2.16*	-1.074*	-2.049	-2.729*	-0.88	-0.521	-0.229	-0.911	-2.337*	-0.421	-1.04	-0.057	-0.707	-1.824*
	Frailty	*B*	-0.057*	-0.077	-0.112*	-0.056*	-0.059*	-0.041*	-0.031*	-0.078*	-0.053*	-0.056*	-0.014*	-0.047*	-0.067*	-0.064*	-0.029
	Gr*frailty	*B*	**0.021**	**0.000**	**-0.013**	**-0.011**	**0.008**	**0.01**	**-0.024**	**-0.02**	**-0.014**	**0.063***	**-0.011**	**-0.003**	**-0.025**	**-0.013**	**0.023**
Chores (Ch)		R²	.221*	.231*	.393*	.154*	.127*	.21*	.187*	.302*	.198*	.146*	.114*	.154*	.239*	.17*	0.09*
	Ch	*B*	-2.003*	-1.861*	-1.786*	-1.67	-1.784*	-1.068	-1.246*	-0.898	-1.15	-1.218*	-0.586	-0.705	-0.107	-1.314	-0.823
	Frailty	*B*	-0.062*	-0.083*	-0.125*	-0.056*	-0.042*	-0.043*	-0.048*	-0.088	-0.057*	-0.024	-0.025*	-0.053*	-0.068*	-0.073*	-0.014
	Ch*frailty	*B*	**0.021**	**0.008**	**0.006**	**-0.012**	**-0.029**	**0.01**	**0.006**	**-0.003**	**-0.006**	**-0.009**	**0.002**	**0.001**	**-0.025**	**0.007**	**-0.018**
Supervision (Su)		R²	.2*	.203*	.36*	.105*	.08*	.203*	.178*	.286*	.181*	.137*	.106*	.147*	.231*	.157*	0.082*
	Su	*B*	-1.403	-1.473	0.641	-0.328	-1.894	0.51	-1.225	0.326	-0.622	-1.31	-1.72	-2.459*	-1.725	-2.519	-1.72
	Frailty	*B*	-0.054*	-0.082*	-0.123*	-0.06*	-0.058*	-0.037*	-0.044*	-0.086*	-0.057*	-0.028*	-0.023*	-0.054*	-0.085	-0.069*	-0.021
	Su*Fr	*B*	**0.019**	**0.009**	**-0.026**	**-0.047**	**-0.001**	**-0.014**	**-0.008**	**-0.029**	**-0.039**	**-0.053**	**0.008**	**0.025**	**0.029**	**0.001**	**-0.031**

Effects are adjusted for age, gender, partnership, educational level and household income; * p < .05

3.3. Properties of care convoys: adequacy

Table 13 shows the interaction effects between care convoy's adequacy and frailty domains on sense of mastery, life satisfaction and meaning in life.

Regarding *physical frailty*, moderation analyses showed a significant interaction effect of physical frailty and receiving sufficient assistance for personal care on sense of mastery (b = -0.091, 95% CI [-0.166, -0.015], t = -2.397, p = .019) (Table 13). Looking at the conditional effects, physical frailty was predictive of less sense of mastery for older adults who received sufficient assistance for personal care (b = -0.044, 95% CI [-0.085, -0.004], t = -2.168, p = .033) but was not predictive for older adults who did not receive sufficient assistance for personal care (b = 0.046, 95% CI [-0.016, 0.109], t = 1.485, p = .142).

There was also a significant interaction effect of physical frailty and receiving sufficient assistance for administration and financial management (b = 0.109, 95% CI [0.036, 0.181], t = 2.962, p = .004) as well as physical frailty and receiving sufficient social company and support (b = 0.1, 95% CI [0.017, 0.183], t = 2.406, p = .02) on life satisfaction. Looking at the conditional effects, physical frailty was predictive of less life satisfaction for both older adults who received sufficient assistance for administration and financial management (b = -0.039, 95% CI [-0.063, -0.015], t = -3.197, p = .02) and older adults who did not receive sufficient assistance for administration and financial management (b = -0.147, 95% CI [-0.218, -0.077], t = -4.149, p < 0.001). But the betas described a significant greater negative relationship for older adults who did not receive sufficient assistance for administration and financial management. Physical frailty was also predictive of less life satisfaction for older adults who did not receive sufficient social company and support (b = -0.088, 95% CI [-0.150, -0.025], t = -2.794, p = 0.007) but was not predictive for older adults who receive sufficient social company and support (b = 0.012, 95% CI [-0.052, 0.077], t = 0.380, p = .706).

Regarding *cognitive frailty*, moderation analyses demonstrated a significant interaction effect of cognitive frailty and being satisfied with the informal care received on meaning in life (b = -0.099, 95% CI [0.016, 0.149], t = 2.426, p = .016). Cognitive frailty was predictive of less meaning in life for both older adults who were satisfied with the informal care received (b = -0.052, 95% CI [-0.07, -0.034], t = -5.573, p < .001) and older adults who were not satisfied with the informal care received (b = -0.134, 95% CI [-0.199, -0.07], t = -4.076, p < .001). But the betas showed a significant greater negative relationship for older adults who were not satisfied with the informal care received.

Regarding *psychological frailty*, moderation analyses described a significant interaction effect of psychological frailty and receiving sufficient assistance for administration and financial management (b = 0.087, 95% CI [0.01, 0.164], t = 2.232, p = .0.027) and psychological frailty and receiving sufficient assistance for chores (b = -0.079, 95% CI [-0.148, -0.01], t = -2.255, p = .025) on life satisfaction. Looking at the conditional effects, psychological frailty was predictive of less life satisfaction for both older adults who received sufficient assistance for administration and financial management (b = -0.104, 95% CI [-0.144, -0.065], t = -5.168, p < .001) and older adults who did not receive sufficient assistance for administration and financial management (b = -0.192, 95% CI [-0.259, -0.124], t = -5.632, p < .001). But the betas described a significant greater negative relationship for older adults who did not receive sufficient assistance for administration and financial management. Psychological frailty was also predictive of less life satisfaction for older adults who received sufficient assistance for chores (b = -0.099, 95% CI [-0.124, -0.073], t = -7.675, p < .001) but was not predictive for older adults who did not receive sufficient assistance for chores (b = -0.02, 95% CI [-0.084, 0.045], t = -0.597, p = .551).

There was also a significant interaction effect of psychological frailty and receiving sufficient assistance for chores on life satisfaction (b = -0.074, 95% CI [-0.141, -0.007], t = -2.174, p = .031). Psychological frailty was predictive of less meaning in life for older adults who received sufficient assistance for chores (b = -0.103, 95% CI [-0.131, -0.075], t = -7.266, p < .001) but not for older adults who did not receive sufficient assistance for chores (b = -0.029, 95% CI [-0.09, 0.033], t = -0.915, p = .361).

Regarding *social frailty*, moderation analyses showed a significant interaction effect of social frailty and receiving sufficient assistance for chores (b = -0.118, 95% CI [-0.201, -0.035], t = -2.797, p = .006) as well as social frailty and being satisfied with the formal care received (b = 0.086, 95% CI [0.020, 0.153], t = 2.545, p = .011) on meaning in life. Looking at the conditional effects, social frailty was predictive of less meaning in life for both older adults who were satisfied with the formal care received (b = -0.065, 95% CI [-0.09, -0.04], t = -5.104, p < .001) and older adults who were not satisfied with the formal care received (b = -0.151, 95% CI [-0.213, -0.089], t = -4.783, p < .001). But the betas indicated a significant greater negative relationship for older adults who were not satisfied with the formal care received. Social frailty was also predictive of less meaning in life for older adults who did not receive sufficient assistance for chores (b = -0.089, 95% CI [-0.123, -0.054], t = -5.052, p < .001) but not for older adults who received sufficient assistance for chores (b = 0.029, 95% CI [-0.047, 0.105], t = -0.751, p = .454).

Regarding *environmental frailty*, moderation analyses demonstrated a significant interaction effect of environmental frailty and receiving sufficient assistance for chores (b = -0.062, 95% CI [-0.121, -0.002], t = -2.038, p = 0.043) and environmental frailty and satisfaction with formal care received (b = 0.093, 95% CI [0.01, 0.176], t = 2.211, p = .028) on sense of mastery. Looking at the conditional effects, environmental frailty was predictive of less sense of mastery for older adults who received sufficient assistance for chores (b = -0.09, 95% CI [-0.133, -0.046], t = -4.083, p < 0.001) but was not predictive for older adults who did not receive sufficient assistance for chores (b = -0.028, 95% CI [-0.068, 0.012], t = -1.389, p = .166). Environmental frailty was also predictive of less sense of mastery for both older adults who were satisfied with the formal care received (b = -0.05, 95% CI [-0.077, -0.023], t = -3.651, p < 0.001) and older adults who were not satisfied with the formal care received (b = -0.143, 95% CI [-0.222, -0.065], t = -3.589, p < 0.001). But the betas indicated a significant greater negative relationship for older adults who were not satisfied with the formal care received.

There was also a significant interaction effect between environmental frailty and receiving sufficient assistance for household tasks (b = 0.111, 95% CI [0.014, 0.207], t = 2.258, p = .025) on life satisfaction, and between environmental frailty and receiving sufficient assistance for personal displacements on meaning in life (b = -0.099, 95% CI [-0.192, -0.005], t = -2.09, p = .039). Environmental frailty was predictive of less life satisfaction for older adults who did not receive sufficient assistance for household tasks (b = -0.108, 95% CI [-0.198, -0.018], t = -2.358, p = 0.019) but was not predictive for older adults who received sufficient assistance for household tasks (b = 0.002, 95% CI [-0.033, 0.038], t = 0.14, p = .888). Environmental frailty was predictive of higher meaning in life for older adults who did not receive sufficient assistance for personal displacements (b = 0.074, 95% CI [0.000, 0.148], t = 1.986, p = .049) but not for older adults who received sufficient assistance for personal displacements (b = -0.024, 95% CI [-0.083, 0.034], t = -0.826, p = .411).

Table 13. Interaction effects between care convoy's adequacy and frailty domains on sense of mastery, life satisfaction and meaning in life (N = 619)

			Sense of mastery					Life satisfaction					Meaning In life				
			Phys. frailty	Cog. frailty	Psych. frailty	Soc. frailty	Envir. frailty	Phys. frailty	Cog. frailty	Psych. frailty	Soc. frailty	Envir. frailty	Phys. frailty	Cog. frailty	Psych. frailty	Soc. frailty	Envir. frailty
Suff. personal care (SPC)		R^2	.209*	.252*	.471*	.215*	.149*	.221*	.156	.335*	.224*	.139	.132	.143	.302*	.204*	0.088
	SPC	*B*	8.68*	0.213	0.156	0.984	1.96	10.769	-4.529	-0.094	-2.838	0.297	3.712	-0.227	3.923	3.276	-0.603
	Frailty	*B*	0.046	-0.08*	-0.133*	-0.076	-0.014	0.079	-0.107	-0.096	-0.127	-0.026	0.022	-0.024	0.019	-0.005	-0.005
	SPC*frailty	*B*	**-0.091***	**0.021**	**0.014**	**0.007**	**-0.018**	**-0.135**	**0.097**	**-0.009**	**0.045**	**-0.006**	**-0.055**	**-0.018**	**-0.11**	**-0.077**	**-0.005**
Suff. household (SHo)		R^2	.159*	.199*	.344*	0.094*	0.07*	.245*	.181*	.306*	.2*	.166*	0.1*	.14*	.22*	.136*	0.058*
	SHo	*B*	-0.997	2.585	0.457	-0.056	0.419	-2.024	1.603	1.431	-2.98	-1.04	-0.817	2.251	2.359	-1.582	-0.071
	Frailty	*B*	-0.066*	-0.033	-0.118*	-0.076	-0.074	-0.075*	-0.014	-0.059*	-0.119	-0.108*	-0.042	0.000	-0.02	-0.1	-0.053
	SHo*frailty	*B*	**0.02**	**-0.046**	**0.000**	**0.020**	**0.034**	**0.034**	**-0.028**	**-0.032**	**0.067**	**0.111***	**0.015**	**-0.056**	**-0.069**	**0.036**	**0.038**
Suff. pers. move. (SPM)		R^2	.18*	.239*	.443*	.145*	.11*	.206*	.212	.31*	.251*	.174*	.131*	.185*	.227*	.177*	.118*
	SPM	*B*	4.227	2.183	2.653	-1.384	1.464	-3.75	3.76	2.282	-3.235	2.867	-0.332	3.373	1.054	4.726	2.59
	Frailty	*B*	-0.006	-0.054	-0.065	-0.098	-0.026	-0.089*	0.032	-0.033	-0.134	0.052	-0.038	0.036	-0.041	0.006	0.074*
	SPM*frailty	*B*	**-0.055**	**-0.034**	**-0.072**	**0.013**	**-0.064**	**0.054**	**-0.086**	**-0.056**	**0.045**	**-0.094**	**0.008**	**-0.094**	**-0.034**	**-0.088**	**-0.099***
Suff. administrat. (SAd)		R^2	.249*	.31*	.422*	.188*	0.091*	.182*	.166*	.351*	.208*	0.092	.237*	.21*	.29*	.166*	.147*
	SAd	*B*	-4.581	1.572	-0.973	-7.16	-2.067	-6.75*	0.721	-3.829*	-3.596	-1.304	-0.618	3.164	1.928	-1.063	3.183
	Frailty	*B*	-0.139	-0.12	-0.158	-0.206	-0.16	-0.147*	-0.085	-0.192*	-0.149	-0.101	-0.086	-0.051	-0.081	-0.098	-0.012
	SAd*frailty	*B*	**0.082**	**0.025**	**0.034**	**0.132**	**0.132**	**0.109***	**0.03**	**0.087***	**0.061**	**0.11**	**0.045**	**0.007**	**0.003**	**0.06**	**0.039**
Suff. social com. (SSC)		R^2	.237	.204	.407*	.192	.16	.297*	.223	.431*	.396*	.209	.126	.152	.405*	.344*	.127
	SSC	*B*	-3.071	2.832	1.175	6.151	0.123	-3.451	4.236	4.63	-4.638	1.209	0.774	3	2.318	-7.649	1.406
	Frailty	*B*	-0.081*	-0.037	-0.102*	-0.027	-0.02	-0.088*	-0.012	-0.062	-0.193*	-0.044	-0.03	-0.018	-0.079	-0.211*	-0.002
	SSC*frailty	*B*	**0.073**	**-0.038**	**-0.021**	**-0.073**	**0.156**	**0.1***	**-0.049**	**-0.08**	**0.125**	**0.123**	**0.014**	**-0.052**	**-0.058**	**0.171**	**0.113**
Suff. groceries (SGr)		R^2	.114*	.217*	.415*	.122*	.078*	.152*	.198*	.341*	.182*	.115*	.1*	.141*	.266*	.139*	0.056
	SGr	*B*	6.583*	3.699	2.978	3.621	2.381	0.001	-0.604	1.037	2.691	-0.221	-0.839	0.806	1.902	3.158	-0.222
	Frailty	*B*	0.027	-0.021	-0.07	-0.036	0.006	-0.023	-0.049	-0.046	-0.018	0.014	-0.03	-0.016	-0.015	-0.014	0.008
	SGr*frailty	*B*	**-0.066**	**-0.061**	**-0.06**	**-0.037**	**-0.064**	**-0.011**	**-0.011**	**-0.063**	**-0.059**	**-0.01**	**-0.001**	**-0.041**	**-0.084**	**-0.069**	**-0.012**
Suff. chores (SCh)		R^2	.146*	.189*	.376*	.117*	.11*	.238*	.208*	.352*	.238*	0.19*	.113*	.136*	.288*	.175*	0.087*
	SCh	*B*	2.376*	1.827	1.669	4.563	1.647	0.19	0.918	2.094	1.46	0.143	2.158	0.897	2.031*	6.126*	1.04
	Frailty	*B*	-0.021	-0.043	-0.089*	-0.006	-0.028	-0.035	-0.01	-0.02	-0.043	-0.023	0.01	-0.02	-0.029	0.029	0.009
	SCh*frailty	*B*	**-0.025**	**-0.035**	**-0.035**	**-0.073**	**-0.062***	**0.000**	**-0.031**	**-0.079***	**-0.033**	**-0.012**	**-0.039**	**-0.034**	**-0.074***	**-0.118***	**-0.057**
Suff. supervision (SSu)		R^2	/	.525	.794*	.527	.532	/	0.598	.83*	.596	.594	/	.865	.711	0.855	0.495
	SSu	*B*	/	18.233	-5.714	-11.743	10.651	/	-17.144	-6.157	-11.904	-8.802	/	6.599	1.701	3.106	-3.044
	Frailty	*B*	/	-0.21	-0.047	-0.181	-0.11	/	-0.17	-0.041	-0.132	-0.108	/	0.036	0.051	-0.049	0.001
	SSu*frailty	*B*	**/**	**0.183**	**-0.079**	**0.13**	**.215**	**/**	**0.158**	**-0.058**	**0.115**	**0.089**	**/**	**-0.109**	**-0.122**	**-0.088**	**-0.039**
Sat. informal care (SIC)		R^2	.201*	.213*	.38*	.112*	0.075*	.173*	.16*	.265	.17*	.107*	.12*	.167*	.259*	.136	.083*
	SIC	*B*	0.967	-0.299	-0.706	2.474	1.187	-1.443	-0.269	0.293	-1.788	0.405	-1.126	-2.266	-2.005	-0.975	-0.071
	Frailty	*B*	-0.041	-0.107*	-0.137*	-0.02	0.004	-0.065*	-0.056	-0.057	-0.076	0.007	-0.053	-0.134*	-0.14*	-0.062	-0.039
	SIC*frailty	*B*	**-0.014**	**0.023**	**0.01**	**-0.055**	**-0.065**	**0.03**	**0.009**	**-0.03**	**0.006**	**-0.034**	**0.027**	**0.082***	**0.056**	**-0.003**	**0.014**
Sat. formal care (SFC)		R^2	.192*	.2*	.37*	0.092	0.09*	.231*	.205*	.313*	.213*	.166*	.1*	.14*	.24*	.153*	.076*
	SFC	*B*	0.589	2.18	0.543	-0.844	-0.358	-1.126	1.163	0.543	-1.386	0.964	-0.789	0.434	0.717	-4.715*	-0.165
	Frailty	*B*	-0.063*	-0.048	-0.127*	-0.092	-0.143*	-0.068*	-0.023	-0.076	-0.089	0.002	-0.036*	-0.029	-0.041	-0.151*	-0.022
	SFC*frailty	*B*	**0.011**	**-0.034**	**0.003**	**0.038**	**0.093***	**0.034**	**-0.02**	**-0.008**	**0.033**	**-0.024**	**0.014**	**-0.024**	**-0.05**	**0.086***	**-0.004**

Effects are adjusted for age, gender, partnership, educational level and household income; * $p < .05$

4. Discussion

The objective of this study was to explore the moderating role of care convoy properties (i.e. structure, function and adequacy) in the relationship between multidimensional frailty (i.e. physical, cognitive, psychological, social and environmental frailty) and wellbeing (i.e. sense of mastery, life satisfaction and meaning in life) in community-dwelling older adults. Therefore, moderation analyses were performed among 619 older care recipients (60+) at risk for frailty in Flanders, Belgium. This study demonstrates that components in the structure and adequacy of frail, older adults' care convoy can serve as balancing factors in the relationship between multidimensional frailty and wellbeing.

First, despite the fact that informal care is mostly understood as family care and little attention has been paid to non-kin caregivers (Lapierre & Keating, 2013), the results of this study demonstrates the possible 'protective' role of friends and neighbours in the relationship between multidimensional frailty and wellbeing. Higher levels of physical, psychological and environmental frailty were associated with lower levels of wellbeing for older adults who did not receive assistance from neighbours, and higher levels of psychological frailty were associated with lower levels of wellbeing for older adults who did not receive assistance from friends/acquaintances. These results are in accordance with other studies highlighting the role of non-kin caregivers in older adults' wellbeing (Gardner, 2011; Merz & HuxHold, 2010). Shaw (2005) indicates that older adults particularly perceive higher levels of care and support from neighbours because they have more frequent neighbour contact and great residential stability. Neighbours often play a compensatory role by supplementing the lack of family and/or professional support (Shaw, 2005). Friends and neighbours are more likely to provide assistance entirely voluntarily, whereas kin members might feel a moral obligation to do so (Merz & Huxhold, 2010).

Second, both dimensions of the adequacy of care convoys, satisfaction and sufficiency, are possible 'protective' factors. In line with studies suggesting that meeting older adults' care needs are 'protective' for their wellbeing (Beach & Schulz, 2017; Hoogendijk et al., 2014; Kadowaki, Wister, & Chappell, 2015), receiving sufficient care for several activities of daily life balanced the relationship between multidimensional frailty and wellbeing. For example, higher levels of physical and psychological frailty were associated with lower levels of wellbeing for older adults who did not receive sufficient assistance for administration and financial management. Higher levels of social and environmental frailty were associated with lower levels of wellbeing for older adults who did not receive sufficient assistance for chores. Unmet care needs are detrimental for older adults. Namely research indicates that 31.8% of older adults in need of assistance report at least one adverse consequence related to unmet care needs within the past month (Freedman & Spillman, 2014).

Adequacy needs to take two dimensions into account: 1) the 'quantitative' dimensions which assesses if the individual is getting sufficient care and support, and 2) the 'qualitative' dimension which evaluates the satisfaction of the care provided (Morrow-Howell et al., 1998). Regarding satisfaction, the results demonstrate a negative relationship between cognitive frailty and wellbeing for older adults who were not satisfied with the informal care received, and between social and environmental frailty and wellbeing for older adults who were not satisfied with the formal care received. The results regarding the qualitative dimension of adequacy are more consistent than the quantitative dimension. Namely for sufficiency, there was a negative relationship between physical frailty and wellbeing for older adults who received sufficient assistance for personal care, and between psychological frailty and wellbeing for older adults who received sufficient assistance for chores. The qualitative evaluation looks like a more prominent balancing factor for the relationship between multidimensional frailty and wellbeing. As Christie et al. (2009) indicate, one must consider that providing care is not only about meeting the basic needs of care recipients but also about paying attention to further preferences.

Our study showed that the function of care convoys does not serve as 'protective' factor for the relationship between multidimensional frailty and wellbeing among older adults. As individuals continue to age, many older adults live with increasing complex health issues and frailty, which affect their daily functioning and overall quality of life (World Health Organization, 2015). Studies indicate the existence of functional differences between types of caregivers. For example, differences in care activities exist between friends/neighbours and family members, as friends and neighbours limit their assistance to practical tasks such as assistance with transport and socio-emotional support (RIS MRC CFAS et al., 1998). Hoefman, Meulenkamp and De Jong (2017) explored the will of the general public to take responsibility for providing care and support. They conclude that the majority of individuals are willing to provide informal care in the future, when necessary. However, individuals are more willing to help for support activities (e.g. administration, accompanying visits), and state that the government holds more responsibility for personal or nursing care. Future research needs to investigate whether receiving help for specific activities from specific caregivers acts as balancing factor for the relationship between multidimensional frailty and wellbeing.

The results of this study underline the need to approach frailty in a multidimensional way. In line with a quantitative study of Dury et al. (2017) who identified different risk profiles for different frailty domains, the study at hand identified different 'protective' factors for the different frailty domains. Using a multidimensional conceptualisation for frailty contributes to integrated care as frail, older adults are addressed from a holistic perspective. In addition to the multidimensional approach towards frailty, one must consider balancing factors in older adults as well. Two individuals with the same level of frailty can be very different in the types of care and support they need, depending on their strengths and resources (Dury et al., 2018; van der Vorst et al., 2017). When considering the structure, function and adequacy of older adults' care convoy as possible balancing factors for the relationship between multidimensional frailty and wellbeing, the results of this study highlight the importance of non-kin caregivers and care convoys' adequacy. Frail, older adults become more dependent of their neighbourhood (Thomése, Buffel, & Phillipson, 2018; Cramm, van Dijk, & Nieboer, 2018). The creation of neighbourhood approaches could reinforce informal community networks to support frail, community-dwelling older adults (van Dijk, Cramm, Birnie, Nieboer, 2016; Smetcoren et al., 2018). Adequacy should contain sufficiency and satisfaction of the care provision. By using both dimensions, a comprehensive approach to the adequacy of care convoys is applied (Dooley, Shaffer, Lance, & Williamson, 2007).

The study has some limitations, which could be addressed. First, this quantitative study used data which has been collected in three municipalities in Belgium and thus the findings of this study cannot be generalised to the total Belgian population. However, as the participants were chosen purposefully, and the communities chosen by the use of specific parameters, we assume that the findings can be applied in other contexts as well. Second, as indication for the function of care convoys this study used needing assistance for eight activities of daily life. However, it is not necessary the case for older adults who indicate to need assistance for a specific activity to actually receive assistance for that activity. Third, the convoy of care model consists of other elements (e.g. care recipients as active participants within their care convoy) which has not been discussed in this study. Future research should consider those elements as protective factors as well for the relationship between multidimensional frailty and wellbeing in older adults. Fourth, care convoys change over time (Kemp et al., 2013). Future research should investigate the dynamic character of older adults' care convoy in relation with frailty, frailty balance and wellbeing by the use of longitudinal data. Finally, care convoys have outcomes not only for the care recipients (e.g. wellbeing), but also for informal caregivers (e.g. level of care burden) and formal caregivers (e.g. job satisfaction) (Kemp et al., 2013). This 'triadic' approach also needs to be considered in future research.

5. Conclusion

In this paper, we explored the moderating role of care convoy properties (i.e. structure, function and adequacy) in the relationship between multidimensional frailty (i.e. physical, cognitive, psychological, social, and environmental frailty) and wellbeing outcomes (i.e. sense of mastery, life satisfaction and meaning in life) in community-dwelling older care recipients. The results indicate that friends and neighbours as well as both dimensions of adequacy are important positive 'balancing' factors for the relationship between multidimensional frailty and wellbeing in older adults. Practitioners and policy makers would benefit from recognizing the multidimensionality of frailty as well as older adults' strengths and resources as balancing factors for the relationship between multidimensional frailty and wellbeing. A broader view on types of caregivers is necessary, as receiving assistance from non-kin caregivers is beneficial for frail, older adults' wellbeing. In order to positively balance the relationship between frailty and wellbeing among older adults, policy and practitioners need to focus on the adequacy of care and should consider the sufficiency of the care provision as well as older adults' satisfaction.

References

Ament, B. H. L., de Vugt, M. E., Verhey, F. R. J., & Kempen, G. I. J. M. (2014). Are physically frail older persons more at risk of adverse outcomes if they also suffer from cognitive, social, and psychological frailty? *European Journal of Ageing*, *11*(3), 213-219. doi: 10.1007/s10433-014-0308-x

Andreasen, J., Lund, H., Aadahl, M., Gobbens, R. J. J., & Sorensen, E. E. (2015). Content validation of the Tilburg Frailty Indicator from the perspective of frail elderly. A qualitative explorative study. *Archives of Gerontology and Geriatrics*, 61(3), 392-399. doi: 10.1016/j.archger.2015.08.017

Battersby, A., & Phillips, L. (2016). In the end it all makes sense: Meaning in life at either end of the adult lifespan. The *International Journal of Aging and Human Development*, *83*(2), 184-204. doi: 10.1177/0091415016647731

Beach, S. R., & Schulz, R. (2017). Family caregiver factors associated with unmet needs for care of older adults. *Journal of the American Geriatrics Society*, 65(3), 560-566. doi: 10.1111/jgs.14547

Christie, J., Smith, G. R., Williamson, G. M., Lance, C. E., Shovali, T. E., & Silva L. (2009). Quality of informal care is multidimensional. *Rehabilitation Psychology*, *54*(2), 173-181.

Collard, R. M., Boter, H., Schoevers, R. A., & Oude Voshaar, R. C. (2012). Prevalence of frailty in community-dwelling older persons: A systematic review. *Journal of the American Geriatrics Society*, *60*(8), 1487-1492. doi: 10.1111/j.1532-5415.2012.04054.x

Cramm, J. M., van Dijk, H. M., & Nieboer, A. P. (2018). The creation of age-friendly environments is especially important to frail older people. *Ageing & Society*, *38*(4), 700-720. doi: 10.1017/S0144686X16001240

Dent, E., & Hoogendijk, E. O. (2014). Psychosocial factors modify the association of frailty with adverse outcomes: A prospective study of hospitalised older people. *BMC Geriatrics*, *14*, 108. doi: 10.1186/1471-2318-14-108

De Roeck, E. E., Dury, S., De Witte, N., De Donder, L., Bjerke, M., De Deyn, P. P., et al. (2018). CFAI-Plus: Adding cognitive frailty as a new domain to the comprehensive frailty assessment instrument. *International Journal of Geriatric Psychiatry*, *33*(7), 941-947. doi: 10.1002/gps.4875

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Schols, J., et al. (2013). The comprehensive frailty assessment instrument: Development, validity and reliability. *Geriatric Nursing*, *34*(4), 274-281. doi: 10.1016/j.gerinurse.2013.03.002

Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment*, *49*(1), 71-75. doi: 10.1207/s15327752jpa4901_13

Dooley, W. K., Shaffer, D. R., Lance, C. G., & Williamson, G. M. (2007). Informal care can be better than adequate: Development and evaluation of the Exemplary Care Scale. *Rehabilitation Psychology*, *52*(4), 359-369. doi: 10.1037/0090-5550.52.4.359

Dury, S., De Roeck, E., Duppen, D., Fret, B., Hoeyberghs, L., Lambotte, D., et al. (2017). Identifying frailty risk profiles of home-dwelling older people: focus on sociodemographic and socioeconomic characteristics. *Aging & Mental Health*, *21*(10), 1031-1039. doi: 10.1080/13607863.2016.1193120

Dury, S., Dierckx, E., van der Vorst, A., Van der Elst, M., Fret, B., Duppen, D., et al. (2018). Detecting frail, older adults and identifying their strengths: results of a mixed-methods study. *BMC Public Health*, *18*, 191. doi: 10.1186/s12889-018-5088-3

Dury, S. (2018). Dynamics in motivations and reasons to quit in a Care Bank: A qualitative study in Belgium. *European Journal of Ageing*. doi: 10.1007/s10433-017-0455-y

Elliot, A. J., Mooney, C. J., Infurna, F. J., & Chapman, B. P. (2018). Perceived control and frailty: The role of affect and perceived health. *Psychology and Aging*, *33*(3), 473-81. doi: 10.1037/pag0000218

Field A. Discovering statistics using IBM SPSS statistics. 5th ed. London: SAGE Publications Ltd; 2018.

Freedman, V. A., & Spillman, B. C. (2014). Disability and care needs among older Americans. *The Milbank Quarterly*, *92*(3), 509-541. doi: 10.1111/1468-0009.12076

Fret, B., Lambotte, D., Van Regenmortel, S., Dury, S., De Witte, N., Dierckx, E., et al. (2017). Socio-demographic, socio-economic and health need differences between types of care use in community-dwelling older adults. *International Journal of Care and Caring*, *1*(3), 351-366. doi: 10.1332/239788217X15027193795897

Gardner, P. J. (2011). Natural neighborhood networks - Important social networks in the lives of older adults aging in place. *Journal of Aging Studies*, *25*(3), 263-271. doi: 10.1016/j.jaging.2011.03.007

Geerts, J., & Van den Bosch, K. (2012). Transitions in formal and informal care utilisation amongst older Europeans: The impact of national contexts. *European Journal of Ageing*, *9*(1), 27-37. doi: 10.1007/s10433-011-0199-z

Gobbens, R. J. J., Schols, J. M. G. A., & van Assen, M. A. L. M. (2017). Exploring the efficiency of the Tilburg Frailty Indicator: a review. *Clinical Interventions in Aging*, *12*, 1739-1752. doi: 10.2147/CIA.S130686

Gobbens, R. J. J., & van Assen, MALM. The prediction of quality of life by physical, psychological and social components of frailty in community-dwelling older people. *Quality of Life Research*, *23*(8), 2289-2300. doi: 10.1007/s11136-014-0672-1

Grenier, A. (2007). Constructions of frailty in the English language, care practice and the lived experience. *Ageing & Society*, *27*(3), 425-445. doi: 10.1017/S0144686X06005782

Hayes, A. F. (2013). *Methodology in the social sciences. Introduction to mediation, moderation, and Conditional Process analysis: A regression-based approach*. New York: The Guilford Press.

Hoefman, R. J., Meulenkamp, T. M., & De Jong, J. D. (2017). Who is responsible for providing care? Investigating the role of care tasks and past experiences in a cross-sectional survey in the Netherlands. *BMC Health Services Research*, *17*, 477. doi: 10.1186/s12913-017-2435-5

Hoogendijk, E. O., Muntinga, M. E., van Leeuwen K. M., van der Horst, H. E., Deeg, D. J. H., Frijters, D. H. M., et al. (2014). Self-perceived met and unmet care needs of frail older adults in primary care. *Archives of Gerontology and Geriatrics*, *58*(1), 37-42. doi: 10.1016/j.archger.2013.09.001

Jacobs, M. T., Broese van Groenou, M. I., Aartsen, M. J., & Deeg, D. J. H. (2018). Diversity in older adults' care networks: The added value of individual beliefs and social network proximity. *The Journals of Gerontology: Series B*, *73*(2), 326-336. doi: 10.1093/geronb/gbw012

Jacobs, M., Van Tilburg, T., Groenewegen, P., & Broese van Groenou, M. (2016). Linkages between informal and formal caregivers in home-care networks of frail older adults. *Ageing & Society*, *36*(8), 1604-1624. doi: 10.1017/S0144686X15000598

Kadowaki, L., Wister, A. V., & Chappell, N. L. (2015). Influence of home care on life satisfaction, loneliness, and perceived stress. *Canadian Journal on Aging*, *34*(1), 75-89. doi: 10.1017/S0714980814000488

Kemp, C. L., Ball, M. M., Morgan, J. C., Doyle, P. J., Burgess, E. O., & Perkins, M. M. (2018). Maneuvering together, apart, and at odds: Residents' care convoys in assisted living. *The Journals of Gerontology: Series B*, *73*(4), e13–e23. doi: 10.1093/geronb/gbx184

Kemp, C. L., Ball, M. M., Morgan, J. C., Doyle, P. J., Burgess, E. O., Dillard, J. A., et al. (2017). Exposing the backstage: Critical reflections on a longitudinal qualitative study of residents' care networks in assisted living. *Qualitative Health Research*, *27*(8), 1190-1202. doi: 10.1177/1049732316668817

Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: Theorizing intersections between formal and informal care. *Journal of Aging Studies*, *27*(1), 15-29. doi: 10.1016/j.jaging.2012.10.002

Khezrian, M., Myint, P. K., McNeil, C., & Murray, A. D. (2017). A review of frailty syndrome and its physical, cognitive and emotional domains in the elderly. *Geriatrics*, *2*(4), 36-45. doi: 10.3390/geriatrics2040036

Koehly, L. M., Ashida, S., Schafer, E. J., & Ludden, A. (2015). Caregiving Networks – Using a Network Approach to Identify Missed Opportunities. *The Journals of Gerontology: Series B*, *70*(1), 143-154. doi: 10.1093/geronb/gbu111

Kojima, G., Iliffe, S., Jivraj, S., & Walters, K. (2016). Association between frailty and quality of life among community-dwelling older people: A systematic review and meta-analysis. *Journal of Epidemiology & Community Health*, *70*(7), 716-721. doi: 10.1136/jech-2015-206717

Lambotte, D., De Donder, L., Van Regenmortel, S., Fret, B., Dury, S., Smetcoren, A.-S., et al. (2018a). Frailty differences in older adults' use of informal and formal care. *Archives of Gerontology and Geriatrics*, *79*, 69-77. doi: 10.1016/j.archger.2018.05.018

Lambotte, D., De Donder, L., De Roeck, E. E., Hoeyberghs, L. J., van der Vorst, A., Duppen, D., et al. (2018b). Randomized controlled trial to evaluate a prevention program for frail community-dwelling older adults: a D-SCOPE protocol. *BMC Geriatrics*, *18*, 194. doi: 10.1186/s12877-018-0875-3

Lapierre, T. A., & Keating, N. (2013). Characteristics and contributions of non-kin carers of older people: a closer look at friends and neighbours. *Ageing & Society*, *33*(8), 1442-1468. doi: 10.1017/S0144686X12000736

Lee, W.-J., Chen, L.-K., Peng, L.-N., Chiou, S.-T., & Chou, P. (2016). Personal mastery attenuates the adverse effect of frailty on declines in physical function of older people. *Medicine (Baltimore)*, *95*(34), e4661. doi: 10.1097/MD.0000000000004661

McCann, S., & Evans, D. (2002). Informal care: The views of people receiving care. *Health and Social Care in the Community*, *10*(4), 221-228. doi: 10.1046/j.1365-2524.2002.00367.x

Means, R., Richards, S., & Smith, R. (2008). *Community care. Policy and practice*. New York: Palgrave Macmillan.

Merz, E.-M., & Huxhold, O. (2010). Wellbeing depends on social relationship characteristics: comparing different types and providers of support to older adults. *Ageing & Society*, *30*(5), 843-857. doi: 10.1017/S0144686X10000061

Morrow-Howell, N., Proctor, E. K., & Dore, P. (1998). Adequacy of care: The concept and its measurement. *Research on Social Work Practice*, *8*(1), 86-102. doi: 10.1177/104973159800800107

Pearlin, L. I., Nguyen, K. B., Schieman, S., & Milkie, M. A. (2007). The life-course origins of mastery among older people. *Journal of Health and Social Behavior*, *48*(2), 164-179. doi: 10.1177/002214650704800205

Prince, M. J., Wu, F., Guo, Y., Robledo, L. M. G., O'Donnell, M., Sullivan, R., et al. (2015). The burden of disease in older people and implications for health policy and practice. *Lancet*, *385*(9967), 549-562.

RIS MRC CFAS, Blamford, C., Gregson, B., Farrow, G., Buck, D., Dowswell, T., et al. (1998). Mental and physical frailty in older people: The costs and benefits of informal care. *Ageing & Society*, *18*(3), 317-354.

Shaw, B. A. (2005) Anticipated support from neighbours and physical functioning during later life. *Research on Aging*, *27*(5), 503–525. doi: 10.1177/0164027505277884

Smetcoren, A.-S., De Donder, L., Duppen, D., De Witte, N., Vanmechelen, O., & Verté, D. (2018). Towards an 'active caring community' in Brussels. In T. Buffel, S. Handler & C. Phillipson (Eds.), *Age-friendly cities and communities. A global perspective* (pp. 97-118). Bristol: Policy Press.

Steger, M. F., Frazier, P., Oishi, S., & Kaler, M. (2006). The meaning in life questionnaire: Assessing the presence of and search for meaning in life. *Journal of Counseling Psychology*, *53*(1), 80-93.

Thomése, F., Buffel, T., & Phillipson, C. (2018). Neighbourhood change, social inequalities and age-friendly communities. In T. Buffel, S. Handler & C. Phillipson (Eds.), *Age-friendly cities and communities. A global perspective* (pp. 33-50). Bristol: Policy Press.

van der Vorst, A., Zijlstra, G. A. R., De Witte, N., Vogel, R. G. M., Schols, J. M. G. A., & Kempen, G. I. J. M. (2017). Explaining discrepancies in self-reported quality of life in frail older people: a mixed-methods study. *BMC Geriatrics*, *17*, 251. doi: 10.1186/s12877-017-0641-y

van Dijk, H. M., Cramm, J. M., Birnie, E., & Nieboer, A. P. (2016). Effects of an integrated neighborhood approach on older people's (health-related) quality of life and well-being. *BMC Research Notes*, *9*, 450. doi: 10.1186/s13104-016-2254-5

Verkerk, M. (2001). The care perspective and autonomy. *Medicine, Health Care and Philosophy*, *4*(3), 289-294. doi: 10.1023/A:1012048907443

Vermeiren, S., Vella-Azzopardi, R., Beckwée, D., Habbig, A.-K., Scafoglieri, A., Jansen, B. et al. (2016). Frailty and the prediction of negative health outcomes: A meta-analysis. *Journal of the American Medical Directors Association*, *17*(12), 1163.e1-1163.e17. doi: 10.1016/j.jamda.2016.09.010

Wilhelmson, K., Fritzell, E., Eklund, K., & Dahlin-Ivanoff, S. (2013). Life satisfaction and frailty among older adults. *Health Psychology Research*, *1*(3), 167-172. doi: 10.4081/hpr.2013.e32

World health Organization. (2015). *World report on aging and health*. Luxembourg: World Health Organization.

Zhang, D., Chan, D. C.-C., Niu, L., Liu, H., Zou, D., Chan, A. T.-Y., et al. (2018). Meaning and its association with happiness, health and healthcare utilization: A cross-sectional study. *Journal of Affective Disorders*, *227*, 795-802. doi: 10.1016/j.jad.2017.11.082

Part 4

Discussion

Chapter 9. General discussion

1. Introduction

Societal and demographic trends have led to a growing need to reorganise health and social care for older adults. Ageing-in-place policies acknowledge the need to arrange and deliver community-care at the local level which is strength-based, person-centred and integrated (Lecovich, 2014).

In order to meet this changing view on health and social care for frail, older adults, a more positive and comprehensive approach towards frailty needs to be adopted (Dury et al., 2018). Furthermore, studies point towards the dynamic state of frailty, as older adults' strengths and resources (cf. balancing factors) can decrease negative experiences of frailty and increase positive outcomes (Gobbens, Schols, & van Assen, 2017; van der Vorst et al., 2017). Within this frailty balance, informal and formal care networks and convoys may be of great importance (Jacobs, Broese van Groenou, Aartsen, & Deeg, 2018; Kemp, Ball, & Perkins, 2013).

However, empirical insights into positive outcomes and care convoys as balancing factor of frail, community-dwelling older adults are lacking. By using a multidimensional approach for frailty (De Roeck et al., 2018; De Witte et al., 2013), an ethics of care perspective (Fine & Glendinning, 2005; Tronto, 1993) and the convoy of care model (Kemp et al., 2013), this dissertation contributes to a comprehensive view on care relationships and broader care needs of frail, community-dwelling older adults. The three research goals of the dissertation, therefore, were exploring (1) the positive outcomes in frail, older care recipients, (2) the use of the convoy of care model in frail, older adults, and (3) care convoys as balancing factor for the relationship between multidimensional frailty and wellbeing.

The current chapter provides a general discussion on the main findings of the dissertation. The four studies included in the four previous chapters (see figure 8) were used to formulate answers and arguments. Subsequently, implications for policy and practice are specified, followed by a discussion of the limitations of the dissertation and suggestions for further research. Finally, this part ends with a general conclusion.

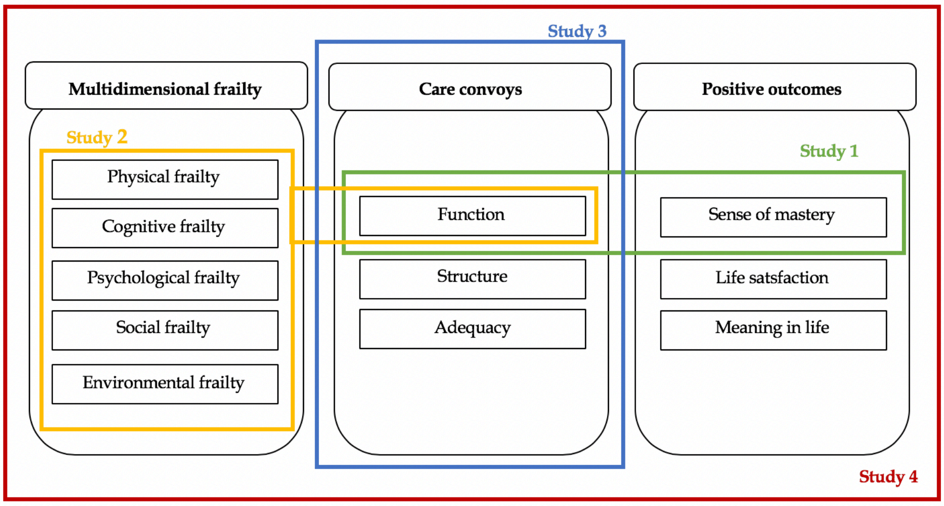


Figure 8. Overview of the dissertation

2. Discussion of the main findings in relation to the research objectives

2.1. Research objective 1: exploring the positive outcomes in frail, community-dwelling older care recipients

In accordance with existing studies (Ament, de Vugt, Verhey, & Kempen, 2014; Lloyd, Kendall, Starr, & Murray, 2016; St John, Tyas, & Montgomery, 2013), study 1, study 3 and study 4 demonstrated that older care recipients, despite experienced deficits and frailty, still feel like having numerous positive outcomes in life. Study 4 reported the average score for sense of mastery, life satisfaction and meaning in life on a scale from 5 to 25, the average score was 19.59 for sense of mastery, 18.81 for meaning in life and 20.09 for life satisfaction. In study 3 frail, older adults stressed in their interview aforementioned positive outcomes but also other positive outcomes like ageing well in place and feeling included in society.

Study 1 and study 3 demonstrated how frail, older adults experienced a sense of mastery within their care process. In general, frail, older adults still experienced a sense of mastery and could feel in control of their daily lives. A first expression of mastery is their statement of needing care, as frail, older adults indicated being conscious of the fact they needed assistance for several activities of daily life. In addition to recognising their care and support needs, frail, older adults organised and asked for care and support. Frail, older adults also tried to change the assistance received when this was not adequate to their needs and wishes.

Study 1 demonstrated that frail, older adults often expressed a sense of mastery within their care process as a relational activity, as they could participate in the different elements of care with the help of their informal caregivers. Frail, older adults often valued relational aspects of mastery because they felt less restricted in daily life. The relational dimension in mastery is also present in other positive outcomes mentioned by frail, older adults (study 3). Frail, older adults in study 3 described the contributions of informal and formal caregivers for their quality of life, life satisfaction, ageing well in place and feeling included in society. For example, informal and formal caregivers supported the feeling of inclusion in society of frail, older adults by stimulating them to go outside and to participate in activities. Several formal care services organised activities outside the home and therefore, provided special transport to pick up older adults. This was of great value for many frail, older adults because otherwise they would not have the possibility to participate.

The relational dimension in positive outcomes suggests informal and formal care as balancing factor for the relationship between multidimensional frailty and wellbeing among older adults. This is further elaborated in the third research objective.

To put it briefly

Although older adults experience lower levels of wellbeing when their frailty increases, frail, community-dwelling older care recipients can experience positive outcomes in life despite their deficits and dependency. Frail, older care recipients mentioned various positive outcomes such as life satisfaction, sense of mastery, ageing well in place and feeling included in society. A relational dimension within positive outcomes needs to be considered as caregivers have important roles in supporting frail, older care recipients to maintain these positive outcomes.

2.2. Research objective 2: exploring the convoy of care model in frail, community-dwellings older adults

Care networks of frail, older adults are diversified, and benefit from being conceptualised as care convoys (Kemp et al., 2013). The use of the convoy of care model facilitates a comprehensive exploration of frail, older adults' care networks. In accordance with Bell and Rutherford (2013) all four studies showed that care networks of frail, older adults are more complex than a simple one-to-one relationship, and comprise a number of facets, each contributing to the wellbeing of frail, older adults.

The structure of care convoys

All four studies confirmed the existence of multiple types of informal and formal caregivers for the provision of care and support to community-dwelling older adults and a great diversity in the composition of their care network (Broese van Groenou, Jacobs, Zwart-Olde, & Deeg, 2016; Jacobs et al., 2018). Study 2 demonstrated the occurrence of eight different combinations of care use among community-dwelling older adults. First, 3 classes of care use were characterised by older adults in need of assistance who were more likely to receive care and support solely from informal caregivers: (1) from nuclear family caregivers only (i.e. spouse and/or children), (2) from nuclear and extended family caregivers (i.e. spouse, children, grandchildren and/or other relatives), and (3) from all types of informal caregivers (i.e. nuclear and extended family, friends/acquaintances and neighbours). Second, 3 classes of care use were characterised by older adults in need of assistance who were more likely to receive care and support from both informal and formal caregivers: (4) from all types of informal caregivers in combination with care from the general practitioner, (5) from all types of informal and formal caregivers (i.e. general practitioner, home nursing and formal home assistance), and (6) informal care from family (both nuclear and extended) in combination with care from all types of formal caregivers. Finally, 2 classes of care use were characterised by older adults in need of assistance who were more likely to receive care and support solely from formal caregivers: (7) from all types of formal caregivers, and (8) formal home assistance only.

Study 2 and study 3 indicated that the majority of care and support is being provided by family caregivers, which also has been demonstrated in previous studies (e.g. Colombo, Llena-Nozal, Mercier, & Tjadens, 2011). However, in accordance with Lapierre and Keating, (2013), non-kin caregivers also contribute significantly to the provision of care and support to frail, community-dwelling older adults. Research suggests that social changes have affected the personal network composition of older adults and observes an absence of age-related decline in non-kin relationships, suggesting the maintenance of non-kin ties to a later age (Suanet, van Tilburg, & Broese van Groenou, 2013).

Also, for frail, older adults, formal care goes beyond the ‘usual’ types of formal caregivers and consider other services (e.g. social service centres, assistive means) and local merchants (e.g. pharmacist, hairdresser) as types of professional support (study 3).

Study 1, study 2 and study 3 showed that care situations often involved both informal and formal caregivers. Similar with the study of Gregory, Mackintosh, Kumar and Grech (2017) this interplay was characterised by negotiation between the care recipient, informal and/or formal caregivers. However, in our studies, when informal and formal caregivers were in touch, care recipients often felt detached from this relationship (study 1 and study 3).

Study 3 demonstrated that frail, older adults experienced different kinds of relationships depending on the specific caregiver. Informal caregivers were not necessarily the closest one to the care recipient. In some cases, participants felt more affection for their formal than informal caregivers.

The function of care convoys

Study 1, study 3 and study 4 showed that frail, older adults require care and support for various activities, including personal care (e.g. preparing medications, bathing, dressing and undressing), home care (e.g. preparing meals, administration, grocery shopping, housecleaning), transportation and socio-emotional support. Study 3 demonstrated that informal and formal care prove to have both their own dynamics as some care tasks are more likely to be provided by specific types of caregivers. In general, personal care and housecleaning were care tasks delivered by formal caregivers while informal caregivers supported frail, older adults principally in other home care activities (e.g. administration), transportation and socio-emotional support. According to Hoefman, Meulenkamp and De Jong (2017), individuals believe that governments are responsible for personal and nursing care activities like bathing or dressing and wound care, while informal caregivers hold more responsibility for social needs and support activities such as support with administration. In study 3, functional differences were also present within informal care as family members cared more extensively while non-kin caregivers provided less intensive care and support, sometimes for the same care activity. This is in line with Naaldenberg, Vaandrager, Koelen and Leeuwis (2012): neighbours are easily approached when needing assistance for small chores as in that case, older adults do not have to rely on family who often live further away. Previous research demonstrated differences in care tasks between kin and non-kin caregivers, namely friends and neighbours limit their assistance to practical tasks such as assistance with transport and socio-emotional support (RIS MRC CFAS et al., 1998). These differences could be the result of differences in motivation to provide care and support: the motivation for family care is often based on obligation and duty (Finch & Mason, 1993; Merz & Huxhold, 2010). This does not apply to the same extent with non-kin caregivers (Atkin, 1992).

Study 1 and study 3 demonstrated the active participation of frail, older adults within their care convoy. First of all, frail, older adults cared for themselves as much as possible. Frail, older adults adapted and found new ways to manage their daily tasks, so they would need less or no assistance. When needing assistance, frail, older adults exerted mastery over their informal and/or formal care and support and tried to actively participate within the care process. Some frail, older adults emphasised self-care as a way to minimise the burden on their informal caregivers. Second, some frail, older adults cared for others while receiving care and support themselves. While some of them took care of loved ones with a high demand for care (e.g. disabled child or spouse) others supported with less intensive care tasks, for example when helping neighbours or taking care of (great-)grandchildren. Third, frail, older adults demonstrated reciprocity within their care relationships and tried to do something in return for their caregivers, for example by providing gifts or financial support, supporting their caregivers or by showing gratitude. Reciprocity also takes form in the idea that one would give assistance if ever needed.

The adequacy of care convoys

Study 3 and study 4 confirmed the distinction between satisfaction and sufficiency within the adequacy of care convoys (Dooley, Shaffer, Lance, & Williamson, 2007; McCann & Evans, 2002; Morrow-Howell, Proctor, & Dore, 1998). Study 3 demonstrated that both dimensions are not necessarily interrelated as frail, older adults who were satisfied with the care and support did not necessarily receive sufficient help, or vice versa.

Study 3 also showed two important aspects which contributed to the extent to which frail, older adults were satisfied with their care convoy, namely being treated with respect and commitment, and caregivers' availability and proximity. With regard to formal care specifically, the time at which formal caregivers provided care and the inability to create a trusting relationship (because of switching professionals) contributed to frail, older adults' dissatisfaction of formal care. Study 1 and study 3 indicated that frail, older adults valued the social contacts within their informal and formal care relationships and attributed positive outcomes to these social relations. Frail, older adults in study 3 indicated their desire for social interactions with their formal caregivers such as the housecleaner, this aspect even had in many cases more value than the help itself. Frail, older adults appreciated the social interactions that resulted from the care and support activities and showed personal attachment towards the individuals who cared for them. Some frail, older adults indicated not having the possibility to develop a relational continuity (e.g. due to lack of time of caregivers, formal caregivers' shifts) and mentioned this as a reason why they were not completely satisfied with their care.

With regard to sufficiency, study 1 and study 3 indicated that informal caregivers do not always have enough time to take care of frail, older adults. Informal caregivers had additional roles besides being an informal caregiver (e.g. proper household, work). Informal caregivers were also sometimes frail themselves. Several studies indicate that informal caregivers carry a great burden, which can have negative consequences for their health and wellbeing (Mello et al., 2017; Oldenkamp, Hagedoorn, Wittek, Stolk, & Smidt, 2017; Ringer et al., 2016). With regard to formal care specifically necessary administration and long waiting lists discouraged frail, older adults to arrange care. Subsequently some frail, older adults receive insufficient formal care due to their low income and the high price of some care possibilities and assistive means.

The dynamic nature of care convoys

The increasing complexity of care needs affect community-dwelling older adults' care convoy. Study 2 and study 3 confirmed research of Geerlings, Pot, Twisk and Deeg (2005), concluding that indicators of need for care (e.g. chronic physical diseases and functional limitations) as well as predisposing and enabling factors inherent to the individual like age and having no partner are important conditions for care transitions.

Based on the theoretical framework for health service utilisation of Andersen and Newman (2005), study 2 highlighted the importance of considering frailty as a need for care (physical and psychological frailty) and as enabling factor (social and environmental frailty) in older adults' care convoy. Significant differences were found when comparing frailty levels within the eight combinations of care use mentioned earlier. In line with several studies, study 2 confirmed that older adults who are more likely to receive care from informal caregivers in combination with care from formal caregivers have a greater need for care and support (Broese van Groenou, Glaser, Tomassini, & Jacobs, 2006; Karlsson, Edberg, Westergren, & Hallberg, 2008; Paraponaris, Davin, & Verger, 2012). Environmental frailty could lead to housing related risks for injuries and falls (Camilloni et al., 2011) and physical health and disease related outcomes caused by the home environment (Mack & Liller, 2010), causing the need for both informal and formal care. Older adults in need of assistance who were more likely to receive informal care solely from nuclear family caregivers or solely from formal caregivers were more socially frail than expected. Older adults with small support networks are more likely to have poor care resources (Stone & Rosenthal, 1996) and social support protects older adults from loneliness (Cacioppo, Hawkley, & Thisted, 2010).

Study 3 demonstrated that care convoys are dynamic. The occurrence of events in frail, older adults' lives bring changes in their care convoy. Those changes were not only inherent to the structure of care convoys, but also to their function and adequacy (both sufficiency and satisfaction). Also, changes were not only inherent to the individual but also to its social environment, including their formal and informal caregivers. Some events caused almost immediate changes (e.g. not allowed to drive anymore) while other events generated gradual changes (e.g. physical deterioration). Some events also caused temporary changes (e.g. surgery) while other events created lasting changes (e.g. illness).

To put it briefly

The use of the convoy of care model facilitates a comprehensive exploration of care networks of frail, community-dwelling older adults. Frail, older adults receive care from multiple types of informal and formal caregivers. Functional differences are distinguished between types of caregivers. The convoy of care model illustrates the relationship-based activity as frail, older adults are more than recipient from care and support, and actively shape their care convoy. Care convoys' adequacy is expressed in terms of sufficiency and satisfaction. Finally, frail, older adults' care convoys are dynamic and evolve over time due to events inherent in the older person or his/her environment.

2.3. Research objective 3: exploring care convoys as balancing factor for frail, community-dwellings older adults' wellbeing

Study 1, study 3 and study 4 demonstrated that care convoys play a role in the dynamic state of frailty and contribute to the balance between frailty and older adults' wellbeing. Several components have shown to be protective for wellbeing among frail, older adults.

As mentioned in the first research objective, frail, older adults experienced relational aspects within positive outcomes, as caregivers helped them to maintain those positive outcomes (study 1 and study 3).

In accordance with Fjordside and Morville (2016), study 1 demonstrated that involving and encouraging frail, older adults to participate in their care situation strengthen their feeling of control. Frail, older adults experienced relational aspects of mastery with their informal caregivers in their care process. Looking at the four elements of care (Tronto, 1993): relational aspects of mastery in the element caring about (i.e. noticing the need for care) contained awareness and recognition about care needs which were disclosed through interaction with others: older adults became aware of their needs by conversing with their informal caregivers. Relational aspects of mastery in the element taking care of (i.e. the commitment someone makes to the needs established in the earlier stage) involved the decision and organisation of care and support in interaction with their informal caregivers and the decision to accept help from their informal caregivers. Relational aspects of mastery within the element care-giving (i.e. providing the care and support needed in order to meet the care needs) contained their proper involvement in the care and support activities by their informal caregivers and by having a say in their care and support. Within the element care-receiving (i.e. care recipients' reactions to the help provided) informal caregivers asked if the care and support met frail, older adults' needs and frail, older adults expressed their dissatisfaction to their informal caregivers.

Involvement is a central aspect within the relational dimension of mastery in frail, older adults' care process (study 1). When frail, older adults were not involved, they did not always agree with the contributions of their informal caregivers. This led in many cases to help which was not appropriate to the needs and wishes of frail, older adults. Previous research already underlined the importance of involving older adults, as levels of autonomy influence perceived experiences of health care (Gregory et al., 2017). Conversely, some frail, older adults did not want to be involved in their care process and completely trust on their informal caregivers. This is in line with several studies indicating that not all older adults wish to have an active role within their care (Levinson, Kao, Kuby, & Thisted, 2005; Say, Murtagh, & Thomson, 2006). Experiencing a sense of mastery also arose in building a trusting relationship rather than actively participating in the care process (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007). In addition, the social aspect of care also acts as balancing factor. Frail, older adults not only valued the social contacts with their caregivers but also attributed positive outcomes to these social relations.

Despite that informal caregiving is mostly understood as family caregiving and little attention has been paid to non-kin caregivers (Lapierre & Keating, 2013), another balancing factor for the relationship between multidimensional frailty and wellbeing lays in the reception of care and support from friends and neighbours (study 4). Higher levels of physical, psychological and environmental frailty were associated with lower levels of wellbeing for older adults who did not receive assistance from neighbours. Higher levels of psychological frailty were associated with lower levels of wellbeing for older adults who did not receive assistance from friends/acquaintances. These results are in accordance with research from Gardner (2011) on neighbourhood networks, which highlights the role of friends and neighbours in older adults' wellbeing. According to Shaw (2005), older adults in particular perceive higher levels of care and support from neighbours due to more frequent neighbour contact and greater residential stability. Proximity and availability are key assets of non-kin informal care (Naaldenberg et al., 2012; Nocon & Pearson, 2000). These elements were also mentioned by frail, older adults in study 3 as elements which contributed to the adequacy (satisfaction) of their care convoy.

The last 'protective' balancing factors within care convoys in this dissertation were both dimensions of adequacy (study 4). Namely receiving sufficient assistance for several activities (e.g. personal care, social company and support) as well as satisfaction with the informal and formal care received moderated the relationship between multidimensional frailty and wellbeing.

In terms of sufficiency, existing studies demonstrate that meeting older adults' care needs increase wellbeing (Beach & Schulz, 2017; Hoogendijk et al., 2014; Kadowaki, Wister, & Chappell, 2015). For example, Kadowaki et al. (2015) conclude that older adults who receive home care and have their home care needs met report higher levels of life satisfaction, and lower levels of loneliness and perceived life stress, than those with unmet needs. In study 4 older adults who did not receive sufficient assistance for administration and financial management had higher levels of physical and psychological frailty and lower levels of wellbeing. Older adults who did not receive sufficient social company and support also had higher levels of physical frailty and lower levels of wellbeing. Older adults who did not receive sufficient assistance for chores had higher levels of social frailty and lower levels of wellbeing. Finally, older adults who did not receive sufficient assistance for household tasks and for personal displacements had higher levels of environmental frailty and lower levels of wellbeing.

In terms of satisfaction, study 4 reported the association of higher levels of cognitive frailty with lower levels of wellbeing for older adults who were not satisfied with the informal care received. Higher levels of social and environmental frailty were associated with lower levels of wellbeing for older adults who were not satisfied with the formal care received. The results regarding satisfaction are more consistent than sufficiency. Namely for sufficiency, there was a negative relationship between physical frailty and wellbeing for older adults who received sufficient assistance for personal care, and between psychological frailty and wellbeing for older adults who received sufficient assistance for chores. Being satisfied with the care and support received looks like a more prominent balancing factor. As Christie et al. (2009) indicate, caregivers must consider that providing care is not only about meeting the basic needs of care recipients but also about paying attention to further preferences.

To put it briefly

Involvement within the care process, receiving care from non-kin caregivers and care convoys' adequacy (containing sufficiency and satisfaction of care convoys) are important positive 'balancing' factors for the relationship between multidimensional frailty and wellbeing in older adults. Although involvement has proven to be an important balancing factor, frail, older adults' needs and preferences within the support of positive outcomes should be assessed.

---

3. Implications for practice and policy

3.1. A multidimensional conceptualisation of frailty

This dissertation recommends the use of the CFAI-Plus, a self-assessment questionnaire to detect self-perceived frailty in older adults, as it allows the identification of multidimensional frailty (De Roeck et al., 2018; Dury et al., 2018). This multidimensionality is a strength considering many frailty assessment instruments make use of biomedical approaches and negative stereotyping of older adults (Fried et al., 2001; Rockwood & Mitnitski, 2007). The CFAI-Plus highlights issues on different domains of functioning (i.e. physical, cognitive, psychological, social and environmental frailty), and thus recognises broader care and support needs in older adults. In line with a quantitative study of Dury et al. (2017), in which different risk profiles for the different frailty domains were identified, study 2 and study 4 also showed discrepancies in the association between care convoy properties and the different multidimensional frailty domains. Study 2 found differences when comparing the different combinations of care use (e.g. older adults who were more likely to combine care from family with care from all types of formal care providers were more physically frail than expected while older adults who were more likely to receive care solely from nuclear family were more socially frail than expected), and study 4 found differences when comparing protective convoy factors to frail, older adults' wellbeing (e.g. receiving sufficient assistance for administration and financial management moderated the relation between psychological frailty and wellbeing while receiving sufficient assistance for chores moderated the relation between environmental frailty and wellbeing).

Using a multidimensional conceptualisation for frailty contributes to the achievement of integrated care, as frail, older adults are addressed from a holistic perspective, and from a health-based integrative approach instead of a disease-based one. In Belgium, the fragmentation of the health and social care system is very prominent (Paulus, Van den Heede, & Mertens, 2012; Willemse et al., 2016). Fragmented care considers only one problem at a time (Stange, 2009), which is thus likely to occur when unidimensional approaches to frailty are used. This results in health problems not being detected nor treated in time, leading to an increasing likelihood of losses in wellbeing, as well as lack of alignment between the various informal caregivers and formal caregivers and services. Integration within and between care providers is particularly important for frail, older adults who require a range of different care and support services.

3.2. The use of positive outcomes in the frailty-balance of frail, older care recipients

Within the frailty balance, one should focus on positive outcomes such as life satisfaction, sense of mastery and inclusion. Care and support focussing on reinforcing competences and on wellbeing respond to the holistic needs of individuals (Huber et al., 2011; Rummery & Fine, 2012). In frailty research, most of the studies focus on adverse frailty outcomes (e.g. hospitalisation, mortality, institutionalisation) rather than positive outcomes.

In line with other studies on positive outcomes in frail, older adults (e.g. Ament et al., 2014), this dissertation revealed that frail, older care recipients still can report positive outcomes, despite their deficits and dependence. A relational dimension within these positive outcomes should be acknowledged in frail, older care recipients. Regarding care convoys, care and support provided by significant others are shown to be important components in supporting the maintenance of these positive outcomes. Study 1 demonstrated that frail, older adults experienced mastery over the care process as a relational activity with their informal caregivers. Study 3 showed that frail, older adults also mentioned this relational dimension in other positive outcomes such as life satisfaction, due to the support of informal and formal caregivers.

3.3. Towards a strengths-based approach in multidimensional frailty

In addition to the multidimensional approach towards frailty, one must consider strengths or balancing factors in older adults as well. Two individuals with the same level of frailty can be very different in the types of care and support they need, depending on their competences and resources. In light of healthy and active ageing principles, it is particularly important to identify resources and the intrinsic power older adults have, instead of focusing on deficits only (Beard, Officer, Cassels, 2016). Moreover, older adults prefer care and support focussing on their competences and resources, instead of deficits (Lette, Braan, van den Berg, & de Bruin, 2015; van Kempen et al., 2012). A study from Warmoth et al. (2016) revealed negative consequences of stereotyping, as individuals who were labelled as frail by others, actually started to feel frail and behave accordingly. This strengths-based approach would be beneficial for frailty prevention programs as it offers the opportunity to get a better understanding of individuals' abilities and resources (Graybael, 2001; Minimol, 2016). By assessing the 'frailty balance' and taking competences and resources of older adults into account, in addition to multidimensional frailty, care and support can be tailored to the specific needs of older adults.

Regarding this frailty balance, different components of the care convoy have shown to balance the relationship between multidimensional frailty and wellbeing in older adults (study 1, study 3 and study 4).

First, involving frail, older adults within their process contributes their sense of mastery. However, as some frail, older adults do not actively want to participate, it is important to assess their needs and preferences in order to support frail, older adults' sense of mastery. Furthermore, variations exist in how frail, older adults wish to be involved (Wolff & Boyd, 2015).

Second, in accordance with Smetcoren et al. (2018), it is important to consider the significance of non-kin caregivers (i.e. neighbours and friends) for supporting frail, older adults. It is known that while ageing, older adults become more dependent on their physical neighbourhoods (Wiles, Leibing, Guberman, Reeve, & Allen, 2012). Scholars report the dynamic interplay between environmental needs and frailty in older adults, and the positive contribution of neighbours in supporting frail, older adults' ability to age in place (Cramm, van Dijk, & Nieboer, 2018; van Dijk et al., 2014). The creation of integrated neighbourhood approaches could reinforce informal community networks to support frail, community-dwelling older adults (van Dijk, Cramm, Birnie, Nieboer, 2016).

Third, care convoy's adequacy, containing both satisfaction and sufficiency, positively influenced the relationship between multidimensional frailty and wellbeing in older adults. Both dimensions need to be considered when providing care and support as it offers a comprehensive view on the adequacy of care convoys (Dooley et al., 2007).

3.4. A relational conceptualisation of care and support

Two factors suggest that care convoys should be understood as social relationships (Lloyd, 2000; Lloyd, Calnan, Cameron, Seymour, & Smith, 2014).

First, the dichotomous portrayal of care and support in which an 'active caregiver' provides assistance to a 'passive care recipient' is not adequate to understand the complex inter-relational nature of care and support (Fine & Glendinning, 2005). Study 1 and study 3 showed that care relationships are characterised by negotiation between care recipients, informal and/or formal caregivers. However, when informal and formal caregivers were in touch, frail, older adults felt in some cases disconnected from this relationship. Care convoys also include (intentional) reciprocal behaviour, as frail, older adults exchange care with their caregivers and indicate they would give assistance if ever needed (study 3). Informal caregivers of frail, older adults were in some cases also frail themselves and in need of care and support (study 1 and study 3). Conversely, some frail, older adults while receiving care also provided help to others. Accordingly, the interconnectedness or interdependence of individuals within care relationships should be recognised (Fine & Glendinning, 2005). Fine and Glendinning (2005, p. 61) define interdependence "*as the result of reciprocity between partners, exchanges between dependent actors over time, and the networking of these relations of dependence*". Care and support would benefit from a person-centred and relationship-based approach, where an individual's preferences, values and needs are assessed, and where all parties are involved in the care process. Informal caregivers carry a great burden, and deterioration in care recipients' health and wellbeing has implications for the health and wellbeing of their informal caregivers (Mello et al. 2017; Oldenkamp et al., 2017). Therefore, professionals should recognise the needs of informal caregivers, engage them as proactive partners in the care process, and focus on their wellbeing as well (Oldenkamp et al., 2017). Policies designed to support informal caregivers must be inclusive of home care policy and vice versa, and should be implemented together (Sims-Gould & Martin-Matthews, 2010).

Second, study 1 and study 3 demonstrated the importance of social contacts within care relationships and the significance of developing a relational continuity with their caregivers. Providing care by the same caregiver over a considerable time is important to generate safety, security and trust in older adults (José, Barros, Samitca, & Teixeira, 2016). The way how most formal home care is delivered hampers this relational continuity (e.g. lack of time, switch between caregivers). Services should aim that formal caregivers can maintain and improve relational continuity with frail, older adults. For example, addressing organisational factors (e.g. fostering the consistency of personnel, reducing the number of visits per professional) and facilitating the development of an ongoing relationship (e.g. training) would improve quality of care and support (Waibel, Vargas, Coderch, & Vàzquez, 2018). Also, informal caregivers should be supported in light of relational community. Frail, older adults namely report a lack of relational continuity with their informal caregivers too. In order to help informal caregivers to fulfil the roles they undertake, policies on informal care should not only focus on the wellbeing of informal caregivers but also on social inclusion. According to Eurocarers (2017) useful measures are: providing financial remuneration, facilitating flexible working hours, allowing to leave from work for care reasons, giving pension credits for care time, providing a right to part-time work, providing training and funding respite care during caregiver holidays.

3.5. Frail, older adults as active participants

Study 1 and study 3 demonstrated that frail, older adults are in many ways – and also wish to be – involved within their care and support. Furthermore, frail, older adults also often actively (want to) shape their care convoy. Therefore, this dissertation recommends recognising frail, older adults as active participants within their care convoy. Policies on ageing often target either older adults by promoting active participation and self-responsibility or dependent older adults by viewing them principally as recipients of care (Angus & Reeve, 2006). However, being 'active' and dependent are not mutually exclusive (Boudiny, 2013). According to Coudin and Alexopoulos (2010), interpersonal interactions are socially constructed and confirm the current beliefs and attitudes of ourselves and of others. If caregivers view older adults as helpless or incompetent, they will obtain nothing but dependence and help-seeking behaviours from older adults. Intervention strategies and services should work on eliminating the stereotypes conveyed by caregivers and focus on positive aspects of care, and empowering and engaging older adults within the different elements of the care process.

3.6. The circle model does not always match with the complexity of care convoys

Although the circle model used by the Flemish Senior Citizens policy plan 2015-2020 (Flemish Government, 2015) contributes to a person-centred and integrated approach of care and support, one must be aware of the importance to consider the entire context of care relationships. The circle model does not always match all the experiences and expectations of frail, older adults. Central in the circle model stands the care recipient. The closest circle to the individual contains informal care from family members, friends and neighbours. The next circle contains informal care from volunteers and community-based support. The last circle contains professional care and support. In addition to the principle of complementarity, the circle starts from the principle of subsidiarity: higher circles receive responsibilities which the lower circles cannot or do not want to (further) exert (Heylen, 2016). The reasoning within this model regards that one first has to rely on itself, followed by broader social networks and at the end on formal care.

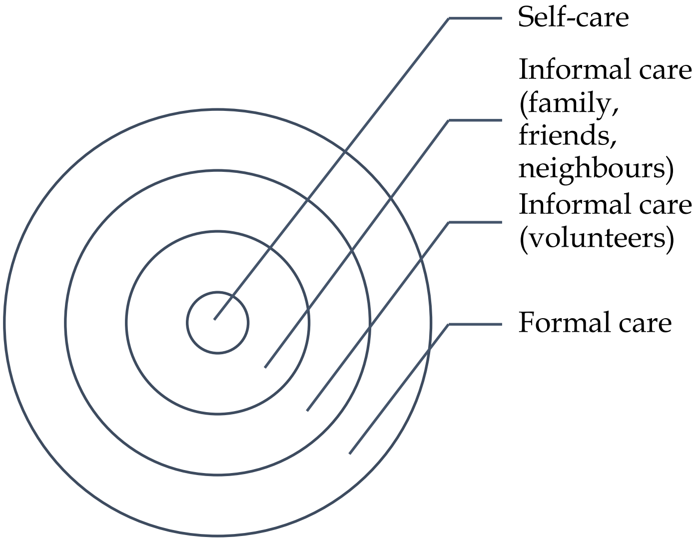


Figure 9. Circle model (Flemish Government, 2015)

However, care networks of frail, community-dwelling older adults are much more complex. Study 2 highlights a relationship of complementarity between informal and formal care among frail, older adults, with the exception for social frailty and when multiple informal and formal caregivers are taken into account. Also, frail, older adults do not necessarily receive informal care, as a considerable amount of frail, older adults in study 2 received solely professional care. Furthermore, informal caregivers are not necessarily the 'closest' one to frail, older adults. Study 3 demonstrated that in some cases, interpersonal interactions and social interactions with formal caregivers were more valued and wanted by frail, older adults. Also, frail, older adults in some cases wished to rely more on their formal than informal caregivers. Finally, policy and practice need to consider functional differences within types of caregivers, as depending on the type of caregiver certain care task are more likely to be provided to frail, older adults (study 3).

4. Limitations of the dissertation and directions for future research

In addition to limitations related to the content of each study, this dissertation in his entirety is also subject to several limitations. Subsequently, this leads to pathways for future research.

4.1. Taking into account the experiences of informal and formal caregivers

In this dissertation, we only included older adults as respondents. It would be of interest to include other convoy members (i.e. informal and formal caregivers) as well, and explore how they reflect on care convoys to further explore the complexity of care convoys. Frail, older adults in this dissertation (study 1 and study 3) revealed that some care situations involved both informal and formal caregivers, however, information on the subject is scarce. Hengelaar et al. (2017) demonstrate the complex, multi-faceted and dynamic interface between informal and formal caregivers. Further research regarding the collaboration between informal and formal care is necessary in order to offer care and support services that are suited to the needs of both the care recipient and informal caregivers (Lindahl, Lidén, & Lindblad, 2010). Moreover, there appear to be differences in the type of care activities provided between informal and formal caregivers. Future research should investigate the repartition of care roles between informal and formal caregivers in order to explore the limits within both types of care.

Also, using perspectives from multiple care convoy members would also enable the use of a multi-informant design, which would improve the likelihood of capturing the complete set of members engaged in the caregiving process (Koehly, Ashida, Schafer, & Ludden, 2015).

4.2. The context in which care convoys of frail, older adults are embedded

Future research on care convoys should consider the implementation of insights from environmental gerontology and ecological perspectives such as the bioecological systems theory (Bronfenbrenner, 1979). The bioecological systems theory focuses on how person–environment transactions influence individuals' functioning over time (Bronfenbrenner, 1979). The model specifies five layers of environmental systems: the micro-, meso-, exo-, maso-, and the chronosystem (Greenfield, 2012). This dissertation has principally focused on frail, older adults' care convoy on a microlevel. Since care networks evolve over time in response to multi-level factors and contexts (Kemp et al., 2013), future research should explore the influence of these factors in frail, older adults' experiences of their care convoy.

The provision of care and support is characterised by spatial dimensions. In Europe, the emphasis on ageing in place and homes as settings for care and support to older adults has become increasingly important (Kendig, 2003; Wiles, 2005). A qualitative study indicates how this emphasis affect the meaning of care recipients' home as place (Stones & Gullifer, 2016). Wiles (2005) argues that we need to understand 'place' as a dynamic, negotiated, contested, contextual and complex process rather than a series of neutral locations for care and support. Who provides care and support is a process of several social and spatial factors, which not only shapes who provides care and support but also the potential impacts of this care provision. International differences concerning policies on home care, the practical organisation of home care and the availability of services also point towards the spatial dimension of care and support (Genet et al., 2011; Suanet, Broese van Groenou, & van Tilburg, 2012).

4.3. Take in account the diversity within frail, older adults and their experiences of care convoys

Several societal and cultural changes (e.g. ageing, migration, changing family structures) lead to a growing diversity within the older population. A group that deserves the attention in future research on care convoys regards frail, older migrants. Many cities in Europe are challenged with a growing number of older migrants (White, 2006). In Brussels, it is estimated that 27% of older adults (65+) have a non-Belgian ethnic background in comparison with only 4% in Flanders (Knowledge Centre Housing & Care Brussels, 2014).

Frail, older migrants have emerged recently on the political agenda (Ahaddour, van den Branden, & Broeckaert, 2016). The challenge for appropriate (culturally sensitive) care and support has become increasingly important for governments. Some interviews in study 3 with frail, older adults who have a migration background already revealed some culturally sensitive components within their care convoy. A recent study of Ahaddour et al. (2016) indicate that care and support for Moroccan and Turkish migrants in Flanders and Brussels remain inaccessible due to several factors such as the language, cultural and religious barriers, financial constraints and a lack of knowledge of health care systems. Furthermore, the study demonstrates that the religious and cultural needs and wishes of Moroccan and Turkish migrants are currently not met by care and support services.

To date, there is a lack of gerontological research with regard to the needs and experiences of ethnic minority groups (Phillipson, 2015). Addressing the needs and wishes of subgroups within the older population is needed to prevent social exclusion (Phillipson, 2015; White, 2006). Furthermore, existing gerontological literature on older adults who have a migration background constructs the 'ethnicity' or ethnic 'culture' as a problem (Zubair & Norris, 2015). Future gerontological research focussing on care convoys of frail, older adults who have a migration background should go beyond the problem-focused and for example study the positive or protective aspects of ethnicity.

4.4. Using other research designs when exploring frail, older adults' care convoy

This dissertation aimed to combine both qualitative and quantitative methodological approaches to explore the dynamics of frail, older adults' care convoy. However, another restriction refers to the data collection method. As study 3 demonstrated by exploring life-events, care convoys are dynamic and change over time (Kemp et al., 2013). The use of a life course perspective would provide a more dynamic and holistic examination of frail, older adults' care convoy (Cohler & Hostetler, 2003). The life course perspective takes into account the historical and societal context of social phenomena (Arber, Fenn, & Meadows, 2014). Life transitions are influenced and shaped by earlier experiences (Robison & Moen, 2000). The life course perspective could be applied by the use of narrative strategies such as life story interviews (Atkinson, 1998). Several studies already used life story interviews for research with older adults (e.g. Browne-Yung, Walker, & Luszcz, 2017; Randall et al., 2015). Using life stories in care settings could counteract ageist attitudes and assumptions (McKeown, Clarke, & Repper, 2006).

Furthermore, the studies included in this dissertation, both quantitative and qualitative, only captured one moment in time. It could be useful to employ longitudinal research designs to investigate more in-depth the evolution of frail, older adults' care convoy and its effects on frail, older adults and their caregivers. Limited studies have used longitudinal data to examine care networks, and principally study transitions in informal and formal care (Geerlings et al., 2005; Geerts & Van den Bosch, 2012). Longitudinal qualitative research has become an emerging methodology over the last decade (Calman, Brunton, Molassiotis, 2013). While qualitative research concerns why and how care convoys are experienced, longitudinal qualitative research focuses on how and why these experiences change over time. In contrast to longitudinal quantitative methodologies, longitudinal qualitative research focuses on individual narratives and trajectories and can capture critical moments and processes involved in change. In order to gain more insights into the trajectories of care convoys longitudinal qualitative research should be considered. Specific attention should be given to the interaction between informal caregivers, between formal caregivers, and between formal with informal caregivers to gain insight into the roles and responsibilities over each convoy member.

5. General conclusion

This dissertation demonstrates that frail, older care recipients still can experience positive outcomes in life, despite experienced deficits and dependence. Within these positive outcomes, a relational dimension needs to be considered as caregivers have important roles in supporting frail, older care recipients to maintain these positive outcomes. In addition to considering multidimensional frailty and positive outcomes, one must consider strengths or balancing factors in older adults as well, as two individuals with the same level of frailty can be very different in the types of care and support they need, depending on their competences and resources. Receiving care from non-kin caregivers and care convoys' adequacy (containing sufficiency and satisfaction of care convoys) are important positive 'balancing' factors for the relationship between multidimensional frailty and wellbeing in older adults. Also, involving frail, older adults within the different element of the care process contributes to frail, older adults' sense of mastery. The social dimension of care also contributes to the frailty balance of older adults suggesting that caregiving is not only instrumental but also involves emotional and personal aspects. By the use of the convoy of care model this dissertation reached a comprehensive understanding of frail, older adults' care networks. Frail, older adults receive care from multiple types of informal and formal caregivers. Within the reception of care and support, functional differences are distinguished between types of caregivers. Moreover, frail, older adults are more than recipients of care and support, and actively shape their care convoy. Care convoys' adequacy is expressed in terms of sufficiency and satisfaction.

This dissertation concludes with recommending the use of ‘frailty balance’, containing multidimensional frailty, balancing factors and positive outcomes. Furthermore, care and support should be conceptualised as relationship-based, while acknowledging care recipients as active members of their care convoy. The complexity of care convoys should also be acknowledged within policies.

Future pathways in research concerning care convoys lay within diversity, ethnicity and additional research methods. More research is also needed to explore meso- and macro-processes on frail, older adults’ care convoy.

References

Ahaddour, C., van den Branden, S., & Broeckaert, B. (2016). Institutional elderly care services and Moroccan and Turkish migrants in Belgium: A literature review. *Journal of Immigrant and Minority Health*, *18*(5), 1216-1227. doi: 10.1007/s10903-015-0247-4

Ament, B. H. L., de Vugt, M. E., Verhey, F. R. J., & Kempen, G. I. J. M. (2014). Are physically frail older persons more at risk of adverse outcomes if they also suffer from cognitive, social, and psychological frailty? *European Journal of Ageing*, *11*(3), 213-219. doi: 10.1007/s10433-014-0308-x

Andersen, R., & Newman, J. F. (2005). Societal and individual determinants of medical care utilization in the United States. *The Milbank Quarterly*, *83*(4), 1-28. doi: 10.1111/j.1468-0009.2005.00428.x

Angus, J., & Reeve, P. (2006). Ageism: A threat to 'aging well' in the 21st century. *Journal of Applied Gerontology*, *25*(2), 137-152. doi: 10.1177/0733464805285745

Arber, S., Fenn, K., & Meadows, R. (2014). Subjective financial well-being, income and health inequalities in mid and later life in Britain. *Social Science & Medicine*, *100*, 12–20. doi: 10.1016/j.socscimed.2013.10.016

Atkin, K. (1992). Similarities and differences between informal carers. In J. Twigg (ed.), *Carers: Research and practice* (pp. 30-58). London: HMSO.

Atkinson, R. (1998). *The Life Story Interview.* Qualitative Research Methods, 44. Thousand Aoks, CA: SAGE Publications.

Bastiaens, H., Van Royen, P., Pavlic, D. R., Raposo, V., & Baker, R. (2007). Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries. *Patient Education and Counseling*, *68*(1), 33-42. doi: 10.1016/j.pec.2007.03.025

Beach, S. R., & Schulz, R. (2017). Family caregiver factors associated with unmet needs for care of older adults. *Journal of the American Geriatrics Society*, *65*(3), 560-566. doi: 10.1111/jgs.14547

Beard, J. R., Officer, A. M., Cassels, A. K. (2016). The world report on ageing and health. *The Gerontologist*, *56*(2), 163-166. doi: 10.1093/geront/gnw037

Bell, D., & Rutherford, A. (2013). Individual and geographic factors in the formation of care networks in the UK. *Population, Space and Place*, *19*(6), 727-737. doi: 10.1002/psp.1792

Boudiny, K. (2013). ‘Active ageing’: From empty rhetoric to effective policy tool. *Ageing & Society*, *33*(6), 1077-1098. doi: 10.1017/S0144686X1200030X

Broese van Groenou, M., Glaser, K., Tomassini, C., & Jacobs, T. (2006). Socio-economic status differences in older people’s use of informal and formal help: A comparison of four European countries. *Ageing & Society*, *26*(5), 745-766. doi: doi.org/10.1017/S0144686X06005241

Broese van Groenou, M., Jacobs, M., Zwart-Olde, I., & Deeg, D. J. H. (2016). Mixed care networks of community-dwelling older adults with physical health impairments in the Netherlands. *Health and Social Care in the Community*, *24*(1), 95-104. doi: 10.1111/hsc.12199

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design.* Cambridge: Harvard University Press.

Browne-Yung, K., Walker, R. B., & Luszcz, M. A. (2017). An examination of resilience and coping in the oldest old using life narrative method. *The Gerontologist*, *57*(2), 282–291. doi: 10.1093/geront/gnv137

Cacioppo, J. T., Hawkley, L. C., & Thisted, R. A. (2010). Perceived social isolation makes me sad: Five year cross-lagged analyses of loneliness and depressive symptomatology in the Chicago health, aging, and social relations study. *Psychology and Aging*, *25*(2), 453-463. doi: 10.1037/a0017216

Calman, L., Brunton, L., & Molassiotis, A. (2013). Developing longitudinal qualitative designs: lessons learned and recommendations for health services research. *BMC Medical Research Methodology*, *13*, 14. doi: 10.1186/1471-2288-13-14

Camilloni, L., Farchi, S., Rossi, P. G., Chini, F., Giorgio, M. D., Molino, N., et al. (2011). A case-control study on risk factors of domestic accidents in an elderly population. *International Journal of Injury Control and Safety Promotion*, *18*(4), 269–276. doi: 10.1080/17457300.2011.562615

Christie, J., Smith, G. R., Williamson, G. M., Lance, C. E., Shovali, T. E., & Silva, L. (2009). Quality of informal care is multidimensional. *Rehabilitation Psychology*, *54*(2), 173-181. doi: 10.1037/a0015705

Cohler, B. J., & Hostetler, A. J. (2003). Linking life course and life story: Social change and the narrative study of lives. In J. Mortimer & R. Shanahan (Eds.), *Handbook of the life course* (pp. 555-78). New York: Kluwer Academic/Plenum Publishing Company.

Colombo, F., Llena-Nozal, A., Mercier, J., & Tjadens, F. (2011). *Help wanted? Providing and paying for long-term care*. Paris: OECD Health Policy Studies, OECD Publishing.

Coudin, G., & Alexopoulos, T. (2010). 'Help me! I'm old!' How negative aging stereotypes create dependency among older adults. *Aging & Mental Health*, *14*(5), 516-523. doi: 10.1080/13607861003713182

Cramm, J. M., van Dijk, H. M., & Nieboer, A. P. (2018). The creation of age-friendly environments is especially important to frail older people. *Ageing & Society*, *38*(4), 700-720. doi: 10.1017/S0144686X16001240

De Roeck, E. E., Dury, S., De Witte, N., De Donder, L., Bjerke, M., De Deyn, P. P., et al. (2018). CFAI-Plus: Adding cognitive frailty as a new domain to the comprehensive frailty assessment instrument. *International Journal of Geriatric Psychiatry*, *33*(7), 941-947. doi: 10.1002/gps.4875

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Schols, J., et al. (2013). The Comprehensive Frailty Assessment Instrument: Development, validity and reliability. *Geriatric Nursing*, *34*(4), 274-281. doi: 10.1016/j.gerinurse.2013.03.002

Dooley, W. K., Shaffer, D. R., Lance, C. G., & Williamson, G. M. (2007). Informal care can be better than adequate: Development and evaluation of the Exemplary Care Scale. *Rehabilitation Psychology*, *52*(4), 359-369. doi: 10.1037/0090-5550.52.4.359

Dury, S., De Roeck, E., Duppen, D., Fret, B., Hoeyberghs, L., Lambotte, D., et al. (2017). Identifying frailty risk profiles of home-dwelling older people: focus on sociodemographic and socioeconomic characteristics. *Aging & Mental Health*, *21*(10), 1031-1039. doi: 10.1080/13607863.2016.1193120

Dury, S., Dierckx, E., Van der Vorst, A., Van der Elst, M., Fret, B., Duppen, D., et al. (2018). Detecting frail, older adults and identifying their strengths: results of a mixed-methods study. *BMC Public Health*, *18*, 191. doi: 10.1186/ s12889-018-5088-3

Eurocarers. (2017). *Overview of carers' needs and existing support measure across Europe*. Retrieved from http://www.eurocarers.org/userfiles/files/factsheets/Eurocarers%20Situation%20of%20carers%20in%20EU.pdf

Finch, J., & Mason, J. (1993). *Negotiating Family Responsibilities*. London: Tavistock/Routledge.

Fine, M., & Glendinning, C. (2005). Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing & Society*, *25*(4), 601-621. doi: 10.1017/S0144686X05003600

Fjordside, S., & Morville, A. (2016). Factors influencing older people's experiences of participation in autonomous decisions concerning their daily care in their own homes: A review of literature. *International Journal of Older People Nursing*, *11*(4), 284-297. doi: 10.1111/opn.12116

Flemish Government. (2015). *Vlaams ouderenbeleidsplan 2015-2020.* Retrieved on 27 September 2018, from https://www.vlaanderen.be/en/nbwa-news-message-document/document/09013557801b11b5

Fried, L. P., Tangen, C. M., Walston, J., Newman, A. B., Hirsch, C., Gottdiener, J., et al., (2001). Frailty in older adults: Evidence for a phenotype. *The Journals of Gerontology: Series A*, *56*(3), M146–M157. doi: 10.1093/gerona/56.3.M146

Gardner, P. J. (2011). Natural neighborhood networks - Important social networks in the lives of older adults aging in place. *Journal of Aging Studies*, *25*(3), 263-271. doi: 10.1016/j.jaging.2011.03.007

Geerlings, S. W., Pot, A. M., Twisk, J. W. R., & Deeg, D. J. H. (2005). Predicting transitions in the use of informal and professional care by older adults. *Ageing & Society*, *25*(1), 111-130. doi: 10.1017/S0144686X04002740

Geerts, J., & Van den Bosch, K. (2012). Transitions in formal and informal care utilisation amongst older Europeans: the impact of national contexts. *European Journal of Ageing*, *9*(1), 27-37. doi: 10.1007/s10433-011-0199-z

Genet, N., Boerma, W. G. W., Kringos, D. S., Bouman, A., Francke, A. L., Fagerström, C., et al. (2011). Home care in Europe: A systematic literature review. *BMC Health Services Research*, *11*, 207. doi: 10.1186/1472-6963-11-207

Gobbens, R. J. J., Schols, J. M. G. A., & van Assen, M. A. L. M. (2017). Exploring the efficiency of the Tilburg Frailty Indicator: A review. *Clinical Interventions in Aging*, *12*, 1739-1752. doi: 10.2147/CIA.S130686

Graybael, C. (2001). Strengths-based social work assessment: Transforming the dominant paradigm. *Families in Society: The Journal of Contemporary Human Services*, *82*(3), 233-242.

Greenfield, E. A. (2012). Using ecological frameworks to advance a field of research, practice, and policy on aging-in-place initiatives. *The Gerontologist*, *52*(1), 1)12. doi: 10.1093/geront/gnr108

Gregory, A., Mackintosh, S., Kumar, S., & Grech, C. (2017). Experiences of health care for older people who need support to live at home: A systematic review of the qualitative literature. *Geriatric Nursing*, *38*(4), 315-324. doi: 10.1016/j.gerinurse.2016.12.001

Hengelaar, A. H., van Hartingsveldt, M., Wittenberg, Y., van Etten-Jamaludin, F., Kwekkeboom, R., & Satink, T. (2018). Exploring the collaboration between formal and informal care from the professional perspective – A thematic synthesis. *Health and Social Care in the Community*, *26*(4), 474-485. doi: 10.1111/hsc.12503

Heylen, L. (2016). Het kleine helpen. Burenhulp is meer dan nostalgie. *Sociaal.net*. Retrieved on 27 September 2018, from https://sociaal.net/analyse-xl/het-kleine-helpen/

Hoefman, R. J., Meulenkamp, T. M., & De Jong, J. D. (2017). Who is responsible for providing care? Investigating the role of care tasks and past experiences in a cross-sectional survey in the Netherlands. *BMC Health Services Research*, *17*, 477. doi: 10.1186/s12913-017-2435-5

Hoogendijk, E. O., Muntinga, M. E., van Leeuwen K. M., van der Horst, H. E., Deeg, D. J. H., Frijters, D. H. M., et al. (2014). Self-perceived met and unmet care needs of frail older adults in primary care. *Archives of Gerontology and Geriatrics*, *58*(1), 37-42. doi: 10.1016/j.archger.2013.09.001

Huber, M., Knottnerus, J. A., Green, L., van der Horst, H., Jadad, A. R., Kromhout, D., et al. (2011). How should we define health? *BMJ*, *343*, d4163. doi: 10.1136/bmj.d4163

Jacobs, M. T., Broese van Groenou, M. I., Aartsen, M. J., & Deeg, D. J. H. (2018). Diversity in older adults' care networks: The added value of individual beliefs and social network proximity. *The Journals of Gerontology: Series B*, *73*(2), 326-336, doi: 10.1093/geronb/gbw012

José, J. d. S., Barros, R., Samitca, S., & Teixeira, A. (2016). Older persons' experiences and perspectives of receiving social care: A systematic review of the qualitative literature. *Health and Social Care in the Community*, *24*(1), 1-11. doi: 10.1111/hsc.12186

Kadowaki, L., Wister, A. V., & Chappell, N. L. (2015). Influence of home care on life satisfaction, loneliness, and perceived stress. *Canadian Journal on Aging*, *34*(1), 75-89. doi: 10.1017/S0714980814000488

Karlsson, S., Edberg, A.-K., Westergren, A., & Hallberg, I. R. (2008). Functional ability and health complaints among older people with a combination of public and informal care vs. public care only. *Scandinavian Journal of Caring Sciences*, *22*(1), 136-148. doi: 10.1111/j.1471-6712.2007.00549.x

Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: Theorizing intersections of formal and informal care. *Journal of Aging Studies*, *27*(1), 15-29. doi: 10.1016/j.jaging.2012.10.002

Kendig, H. (2003). Directions in environmental gerontology: A multidisciplinary field. *The Gerontologist*, *43*(5), 611–614, doi: 10.1093/geront/43.5.611

Koehly, L. M., Ashida, S., Schafer, E. J., & Ludden, A. (2015). Caregiving networks – Using a network approach to identify missed opportunities. *The Journals of Gerontology: Series B*, *70*(1), 143–154. doi: 10.1093/geronb/gbu111

Knowledge Centre Housing & Care Brussels (2014). *Masterplan Woonzorg Brussel 2014-2020*. Retrieved on 25 September 2018, from http://www.woonzorgbrussel.be/node/663

Lapierre, T. A., & Keating, N. (2013). Characteristics and contributions of non-kin carers of older people: A closer look at friends and neighbours. *Ageing & Society*, *33*(8), 1442-1468. doi: 10.1017/S0144686X12000736

Lecovich, E. (2014). Aging in place: From theory to practice. *Anthropological notebooks*, *20*(1), 21-33.

Lette, M., Baan, C. A., van den Berg, M., & de Bruin, S. R. (2015). Initiatives on early detection and intervention to proactively identify health and social problems in older people: experiences from the Netherlands. *BMC Geriatrics*, *15*, 143. doi: 10.1186/s12877-015-0131-z

Levinson, W., Kao, A., Kuby, A., & Thisted, R. A. (2005). Not all patients want to participate in decision making: A national study of public preferences. *Journal of General Internal Medicine*, *20*(6), 531-535. doi: 10.1111/j.1525-1497.2005.04101.x

Lindahl, B., Lidén, E., & Lindblad, B. (2010). A meta-synthesis describing the relationships between patients, informal caregivers and health professionals in home-care settings. *Journal of Clinical Nursing*, *20*(3-4), 454-463. doi: 10.1111/j.1365-2702.2009.03008.x

Lloyd, L. (2000). Caring about carers: Only half the picture? *Critical Social Policy*, *20*(1), 136-150. doi: 10.1177/026101830002000106

Lloyd, A., Kendall, M., Starr, J. M., & Murray, S. A. (2016). Physical, social, psychological and existential trajectories of loss and adaptation towards the end of life for older people living with frailty: A serial interview study. *BMC Geriatrics*, *16*, 176. doi: 10.1186/s12877-016-0350-y

Lloyd, L., Galnan, M., Cameron, A., Seymour, J., & Smith, R. (2014). Identity in the fourth age: Perseverance, adaptation and maintaining dignity. *Ageing & Society*, *34*(1), 1-19. doi: 10.1017/S0144686X12000761

Mack, K. A., & Liller, K. D. (2010). Home injuries: Potential for prevention. *American Journal of Lifestyle Medicine*, *4*(1), 75–81. doi: 10.1177/ 1559827609348476

McCann, S., & Evans, D. (2002). Informal care: The views of people receiving care. *Health and Social Care in the Community*, *10*(4), 221-228. doi: 10.1046/j.1365-2524.2002.00367.x

McKeown, J., Clarke, A., & Repper, J. (2006). Life story work in health and social care: Systematic literature review. *Journal of Advanced Nursing*, *55*(2), 237-247. doi: 10.1111/j.1365-2648.2006.03897.x

Mello, J. d. A., Van Durme, J. M. T., Cès, S., Spruytte, N., Van Audenhove, C., & Declercq, A. (2017). The determinants of informal caregivers' burden in the care of frail older persons: a dynamic and role-related perspective. *Aging & Mental Health*, *21*(8), 838-843. doi: 10.1080/13607863.2016.1168360

Merz, E.-M., & Huxhold, O. (2010). Wellbeing depends on social relationship characteristics: comparing different types and providers of support to older adults. *Ageing & Society*, *30*(5), 843-857. doi: 10.1017/S0144686X10000061

Minimol, K. (2016). Risk assessment and strengths based case management in elderly care – Scope of social work practice. *Artha – Journal of Social Sciences*, *15*(2), 121-133. doi: 10.12724/ajss.37.7

Morrow-Howell, N., Proctor, E. K., & Dore, P. (1998). Adequacy of care: The concept and its measurement. *Research on Social Work Practice*, *8*(1), 86-102. doi: 10.1177/104973159800800107

Naaldenberg, J., Vaandrager, L., Koelen, M., & Leeuwis, C. (2012). Aging populations' everyday life perspectives on healthy aging. New insights for policy and strategies at the local level. *Journal of Applied Gerontology*, *31*(6), 711-733. doi: 10.1177/0733464810397703

Nocon A., & Pearson M. (2000). The roles of friends and neighbours in providing support for older people. *Ageing & Society*, *20*(3), 341–367.

Oldenkamp, M., Hagedoorn, M., Wittek, R., Stolk, R., & Smidt, N. (2017). The impact of older person's frailty on the care-related quality of life of their informal caregiver over time: Results from the TOPICS-MDS project. *Quality of Life Research*, *26*(10), 2705-2716. doi: 10.1007/s11136-017-1606-5

Paraponaris, A., Davin, B., & Verger, P. (2012). Formal and informal care for disabled elderly living in the community: An appraisal of French care composition and costs. *The European Journal of Health Economics*, *13*(3), 327-336. doi: 10.1007/s10198-011-0305-3

Paulus, D., Van den Heede, K., & Mertens, R. (2012). *Position paper: Organisation of care for chronically ill patients in Belgium. Health Services Research (HSR)*. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE).

Phillipson, C. (2015). Placing ethnicity at the centre of studies of later life: theoretical perspectives and empirical challenges. *Ageing & Society*, *35*(5), 917-934. doi: 10.1017/S0144686X14001032

Randall, W., Baldwin, C., McKenzie-Mohr, S., McKim, E., & Furlong, D. (2015). Narrative and resilience: A comparative analysis of how older adults story their lives. *Journal of Aging Studies*, *34*, 155-161. doi: 10.1016/j.jaging.2015.02.010

Ringer, T. J., Hazzan, A. A., Kennedy, C. C., Karampatos, S., Patterson, C., Marr, S., et al. (2016). Care recipients' physical frailty is independently associated with subjective burden in informal caregivers in the community setting: a cross-sectional study. *BMC Geriatrics*, *16*, 186. doi: 10.1186/s12877-016-0355-6

RIS MRC CFAS, Blamford, C., Gregson, B., Farrow, G., Buck, D., Dowswell, T., et al. (1998). Mental and physical frailty in older people: The costs and benefits of informal care. *Ageing & Society*, *18*(3), 317-354.

Robison, J. T., & Moen, P. (2000). A life-course perspective on housing expectations and shifts in late midlife. *Research on Aging*, *22*(5), 499–532. doi: 10.1177/0164027500225003

Rockwood, K., & Mitnitski, A. (2007). Frailty in relation to the accumulation of deficits. *The Journals of Gerontology: Series A*, *62*(7), 722–727. doi: 10.1093/gerona/62.7.722

Rummery, K., & Fine, M. (2012). Care: A critical review of theory, policy and practice. *Social Policy & Administration*, *46*(3), 321-343. doi: 10.1111/j.1467-9515.2012.00845.x

Say, R., Murtagh, M., & Thomson, R. (2006). Patients' preference for involvement in medical decision making: A narrative review. *Patient Education and Counseling*, *60*(2), 102-114. doi: 10.1016/j.pec.2005.02.003

Shaw, B.A. (2005). Anticipated support from neighbours and physical functioning during later life. *Research on Aging*, *27*(5), 503–525. doi: 10.1177/0164027505277884

Sims-Gould, J., & Martin-Matthews, A. (2010). We share the care: Family caregivers' experiences of their older relative receiving home support services. *Health and Social Care in the Community*, *18*(4), 415-423. doi: 10.1111/j.1365-2524.2010.00913.x

Smetcoren, A.-S., De Donder, L., Duppen, D., De Witte, N., Vanmechelen, O., & Verté, D. (2018). Towards an 'active caring community' in Brussels. In T. Buffel, S. Handler & C. Phillipson (Eds.), *Age-friendly cities and communities. A global perspective* (pp. 97-118). Bristol: Policy Press.

Stange, K. C. (2009). The problem of fragmentation and the need for integrative solutions. *The Annals of Family Medicine*, *7*(2), 100-103. doi: 10.1370/afm.971

St John, P. D., Tyas, S. L., & Montgomery, P. R. (2013). Life satisfaction and frailty in community-based older adults: Cross-sectional and prospective analyses. *International Psychogeriatrics*, *25*(10), 1709-1716. doi: 10.1017/S1041610213000902

Stone, L., & Rosenthal, C. (1996). Profiles of the social networks of Canada's elderly: An analysis of 1990 General Social Survey data. In H. Litwin (Ed.), *The social networks of older people: A Cross-national analysis* (pp. 77-97). Westport: Praeger Publishers.

Stones, D., & Gullifer, J. (2016). 'At home it's just so much easier to be yourself': Older adults' perceptions of ageing in place. *Ageing & Society*, *36*(3), 449-481. doi: 10.1017/So144686X14001214

Suanet, B., Broese van Groenou, M., & van Tilburg, T. (2012). Informal and formal home-care use among older adults in Europe: Can cross-national differences be explained by societal context and composition? *Ageing & Society*, *32*(3), 491-515. doi: 10.1017/S0144686X11000390

Suanet, B., van Tilburg, T. G., & Broese van Groenou, M. I. (2013). Nonkin in older adults' personal networks: More important among later cohorts? *The Journals of Gerontology: Series B*, *68*(4), 633-643. doi: 10.1093/geronb/gbt043

Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care*. London: Routledge.

van der Vorst, A., Zijlstra, G. A. R., De Witte, N., Vogel, R. G. M., Schols, J. M. G. A., Kempen, G. I. J. M., et al. (2017). Explaining discrepancies in self-reported quality of life in frail older people: a mixed-methods study. *BMC Geriatrics*, *17*, 251. doi: 10.1186/s12877-017-0641-y van Dijk, H. M., Cramm, J. M., Birnie, E., & Nieboer, A. P. (2016). Effects of an integrated neighborhood approach on older people's (health-related) quality of life and well-being. *BMC Research Notes*, *9*, 450. doi: 10.1186/s13104-016-2254-5

van Kempen, J. A. L., Robben, S. H. M., Zuidema, S. U., Rikkert, M. G. M. O., Melis, R. J. F., & Schers, H. J. (2012). Home visits for frail older people: A qualitative study on the needs and preferences of frail older people and their informal caregivers. *British Journal of General Practice*, *62*(601), e554-e560. doi: 10.3399/bjgp12X653606

Waibel, S., Vargas, I., Coderch, J., & Vàzquez, M.-L. (2018). Relational continuity with primary and secondary care doctors: A qualitative study of perceptions of users of the Catalan national health system? *BMC Health Services Research*, *18*, 257. doi: /10.1186/s12913-018-3042-9

Warmoth, K., Lang, I. A., Phoenix, C., Abraham, C., Andrew, M. K., Hubbard, R. E., et al. (2016). 'Thinking you're old and frail': A qualitative study of frailty in older adults. *Ageing & Society*, *36*(7), 1483-1500. doi: 10.1017/S0144686X1500046X

White, P. (2006). Migrant populations approaching old age: Prospects in Europe. *Journal of Ethnic and Migration Studies*, 32(8), 1283-1300. doi: 10.1080/13691830600927708

Wiles, J. (2005). Conceptualising place in the care of older people: the contributions of geographical gerontology. *International Journal of Older People Nursing in association with Journal of Clinical Nursing*, *14*(8b), 100-108. doi: 10.1111/j.1365-2702.2005.01281.x

Wiles, J. L., Leibing, A., Guberman, N., Reeve, J., & Allen, R. E. S. (2012). The meaning of 'aging in place' to older people. *The Gerontologist*, *52*(3), 357-366. doi: 10.1093/geront/gnr098

Willemse, E., Anthierens, S., Farfan-Portet, M. I., Schmitz, O., Macq, J., Bastiaens, H., et al. (2016). Do Informal caregivers for elderly in the community use support measures? A qualitative study in five European countries. *BMC Health Services Research*, *16*, 270. doi: 10.1186/s12913-016-1487-2

Wolff, J. L., & Boyd, C. M. (2015). A look at person-centered and family-centered care among older adults: Results from a national survey. *Journal of General Internal Medicine*, *30*(10), 1497-1504. doi: 10.1007/s11606-015-3359-6

Zubair, M., & Norris, M. (2015). Perspectives on ageing, later life and ethnicity: Ageing research in ethnic minority contexts. *Ageing & Society*, *35*(5), 897-916. doi: 10.1017/S0144686X14001536

List of publications and contributions

Publications in scientific journals with an international referee system

---

Lambotte, D., Kardol, M. J. M., Schoenmakers, B., Fret, B., Smetcoren, A.-S., De Roeck, E. E., et al. (2018). Relational aspects of mastery for frail, older adults: The role of informal caregivers in the care process. *Health and Social Care in the Community*. doi: 10.1111/hsc.12676

Lambotte, D., De Donder, L., De Roeck, E.E., Hoeyberghs, L., van der Vorst, A., Duppen, D., et al. (2018). Randomized controlled trial to evaluate a prevention program for frail community- dwelling older adults: a D-SCOPE protocol. *BMC Geriatrics*, *18*, 194-205. doi: 10.1186/s12877-018-0875-3

Lambotte, D., De Donder, L., Van Regenmortel, S. Fret, B., Dury, S., Smetcoren, A.-S., et al. (2018). Frailty differences in older adults' use of informal and formal care. *Archives of Gerontology and Geriatrics*, *79*, 69-77. doi: 10.1016/j.archger.2018.05.018

Duppen, D., **Lambotte, D.**, Smetcoren A.-S., Dierckx, E., Fret, B., Switsers, L., et al. (2018). Ageing well in place: kwaliteitsvol thuis wonen met 24-uurszorggarantie. *Verpleegkunde*, *33*(2), 6-13.

Dury, S., Dierckx, E., Van der Vorst, A., Van der Elst, M., Fret, B., Duppen, D., Hoeyberghs, L., De Roeck, E., **Lambotte, D.**, et al. (2018). Detecting frail, older adults and identifying their strengths: results of a mixed-methods study. *BMC Public Health*, *18*, 191-203. doi: 10.1186/ s12889-018-5088-3

Smetcoren, A.-S., Dury, S., De Donder, L., Dierckx, E., De Witte, N., Engelborghs, S., De Deyn, P. P., van der Vorst, A., Van der Elst, M., **Lambotte, D.**, et al. (2018). Detectie en preventie van kwetsbaarheid: Op zoek naar risicoprofielen voor fysieke, psychische, sociale en omgevingskwetsbaarheid. *Tijdschrift voor Gerontologie en Geriatrie*, *49*(1), 1-11. doi: 10.1007/s12439-017-0241-5

Fret, B., **Lambotte, D.**, Van Regenmortel, S., Dury, S., De Witte, N., Dierckx, E., et al. (2017). Socio-demographic, socio-economic and health need differences between types of care use in community-dwelling older adults. *International Journal of Care and Caring, 1*(3), 351-366. doi: 10.1332/239788217X15027193795897

Dury, S., De Roeck, E., Duppen, D., Fret, B., Hoeyberghs, L., **Lambotte, D.**, et al. (2017). Identifying frailty risk profiles of home-dwelling older people: focus on sociodemographic and socioeconomic characteristics. *Aging & Mental Health, 21*(10), 1031-1039. doi: 10.1080/13607863.2016.1193120

Van Regenmortel, S., De Donder, L., Smetcoren, A.-S., **Lambotte, D.**, De Witte, N., Verté, D. (2017). Accumulation of disadvantages: prevalence and categories of old-age social exclusion in Belgium. *Social Indicators Research*, 1-22. doi: doi.org/10.1007/s11205-017-1817-8

Duppen, D., Van der Elst, M. C. J., Dury, S., **Lambotte, D.**, De Donder, L., & D-SCOPE. (2017). The social environment's relationship with frailty: Evidence from existing studies. *Journal of Applied Gerontology*, 1-24. doi: 10.1177/0733464816688310

Commissioned reports of research projects

De Donder, L., Duppen, D., **Lambotte, D.**, Switsers, L., Smetcoren, A.-S., Dierckx, E., et al. Welbevinden in het zorg24 traject: Een kwalitatieve analyse van de verhalen van ouderen zelf. In Solidariteit voor het Gezin (Ed.), *Zorg24, thuiszorg een stap verder. Het thuiszorgmodel van de toekomst* (pp. 121-140). Brussel: Solidariteit voor het Gezin.

De Donder, L., Smetcoren, A.-S., Dury, S., Van Regenmortel, S., **Lambotte, D.**, Duppen, D., et al. (2017). *Zorginnovatie in Vlaamse proeftuinen: Onderzoek naar Actief Zorgzame Buurten in Brussel en Antwerpen*. Brussel: Vrije Universiteit Brussel.

De Donder, L., Smetcoren, A.-S., Van Regenmortel, S., Duppen, D., **Lambotte, D.**, & Fret, B. (2016). *Actief Zorgzame Buurt: Terugblik en eindevaluatie*. Brussel: Vrije Universiteit Brussel.

De Donder, L., Smetcoren, A.-S., Dury, S., Van Regenmortel, S., **Lambotte, D.**, Duppen, B., et al. (2015). *Actief Zorgzame Buurt 2015: Een tussentijdse evaluatie*. Brussel: Vrije Universiteit Brussel.

De Donder, L., Dury, S., Smetcoren, A.-S., Van Regenmortel, S., Verte, E., De Witte, N., Brosens, D., & **Lambotte, D.** (2014). *Actief Zorgzame Buurt: Noden en verwachtingen - een stakeholdersbevraging*. Brussel: Vrije Universiteit Brussel.

Vulgarising publications

Smetcoren, A.-S., **Lambotte, D.**, Duppen, D., Fret, B., & D-SCOPE Consortium (Eds.). (2016). *D-SCOPE. Naar een brede kijk op kwetsbaarheid bij ouderen*. Kessel-Lo: Van der Poorten Uitgeverij.

Personal communications at conferences as 1st author (national and international)

Lambotte, D., De Donder, L., Kardol, M. J. M., & D-SCOPE Consortium. (2018). Informal care as balancing factor for mastery of frail community-dwelling older adults. Symposium presentation at the 4th Nordic Congress of Gerontology, Oslo, Norway.

Lambotte, D., De Donder, L., Smetcoren, A.-S., Kardol, T., & BAS team. (2017). Care convoys within an active caring community. Symposium presentation at the *21st International IAGG World Congress of Gerontology & Geriatrics*, San Francisco, California, USA.

Lambotte, D., Fret, B., Kardol, T., De Donder, L., & D-SCOPE Consortium. (2017). Perspectives of community-dwelling older people receiving informal care on frailty, quality of life and autonomy. Poster presentation at the *21st International IAGG World Congress of Gerontology & Geriatrics*, San Francisco, California, USA.

Lambotte, D., Kardol, M. J. M., Smetcoren, A.-S., & De Donder, L. (2017). How can care convoys contribute to an age friendly Brussels? Symposium presentation at the *46th annual BSG conference*, Swansea University, UK.

Lambotte, D., Kardol, M. J. M., De Donder, L., & D-SCOPE Consortium. (2017). The role of informal care in the mastery of frail older people. Oral presentation at the *46th annual BSG conference*, Swansea University, UK.

Lambotte, D., Kardol, T., De Donder, L., Van Regenmortel, S., Smetcoren, A.-S., Marsillas, S., et al. (2016). Social contacts and active ageing: The role of social networks in the sport participation of divorced older adults. Symposium presentation at the *45th annual British Society of Gerontology conference*, University of Stirling, UK.

Lambotte, D., De Donder, L., Kardol, T., & D-SCOPE Consortium. (2016). Use of informal and formal care of community-dwelling older adults. Frailty differences in older adult's care utilisation. Symposium presentation at the *45th annual British Society of Gerontology conference*, University of Stirling, UK.

Lambotte, D., Van Regenmortel, S., Fret, B., Dury, S., De Donder, L., Kardol, T., et al. (2016). Does informal care substitute for formal care? Informal and formal care use among frail community-dwelling older people. Poster presentation at the *39ste Wintermeeting, Belgische Vereniging voor Gerontologie en Geriatrie*, Ostend, Belgium.

Lambotte, D., Kardol, T., De Donder, L., Van Regenmortel, S., Dury, S., & Fret, B. (2015). The relation between care use and frailty among community-dwelling older people. Oral presentation at the 2nd *ULB-VUB Joint PhD Day in Psychology and Educational Sciences*, Brussels, Belgium.

Lambotte, D., Kardol, T., De Donder, L., & Dury, S. (2015). Informal care of frail older people: Research plan. Poster presentation at the *4th MICRA PhD Conference*, Manchester, UK.