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FRAILTY IN LATER LIFE: A FOCUS ON THE SOCIAL ENVIRONMENT AND POSITIVE OUTCOMES

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The moment we institutionalise older adults just because they feel lonely, we have failed as a society

- Bernadette Van den Heuvel -

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If you want to go fast, go alone. If you want to go far, go together

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PART I - BACKGROUND AND RESEARCH METHODS

CHAPTER 1

GENERAL INTRODUCTION

1 Abstract

This chapter presents a general introduction for the studies that form this PhD-dissertation. After a background on the emergence of ageing and its consequences, a comprehensive introduction on different topics is presented to gain insight in (a) ageing research, (b) ageing policy and (c) frailty in later life. In the ageing in research section, attention is given to environmental and social gerontology theories. For ageing policy, the regulations on the local level are specified as well as the regional and international level. The third section details the conceptualisations and operationalisations of frailty in later life and focusses further on frailty outcomes. This chapter ends with the research aims of the PhD and presents a structure of the studies.

2 Population ageing: more years in life

The population we live in is ageing. In most developing countries, life expectancy is increasing with no sign of deceleration (Christensen, Doblhammer, Rau, & Vaupel, 2009). It is a myth that discoveries in modern medicine is the sole cause that leaded to longer lives of people than ever before (de Medeiros, 2017). Instead, population ageing is caused by a combination of factors (Petrovic, 2008). First, many western countries had a *babyboom* after the second World War and during this period, more than average children were born (Petrovic, 2008). Second, life expectancy is powerfully driven by the infant mortality rate, which has been decreased drastically since 1950 worldwide (Bloom, 2011). Already in 1906, the British physician Sir George Newman was a pioneer with his studies on the complex context of infant mortality and argued that infant mortality was a social problem rather than a medical problem (Wolf, 2007). Health behaviours, biological factors, psychosocial factors and health care, including prenatal care have a relationship with birth outcomes (Kim & Saada, 2013). These individual factors are structurally and socially determined by health inequities in an individual's socioeconomic position (e.g. education, occupation and income) but also the individual's socioeconomic and political context such as governance, socioeconomic policies (e.g. labour market, housing) and public policies (e.g. education, health, social protection) (Kim & Saada, 2013; Solar & Irwin, 2010).

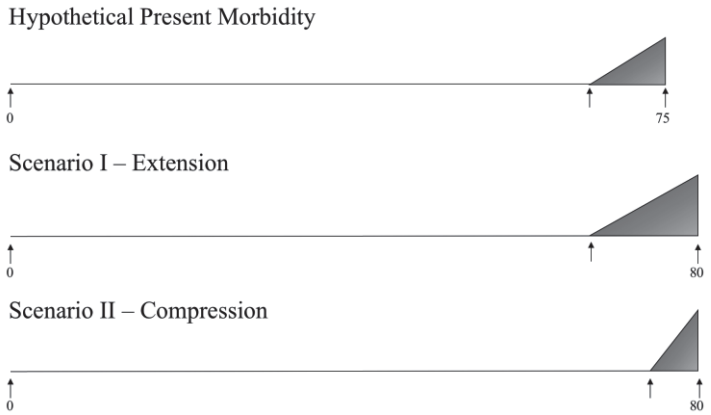
In Belgium, 16.1% of the population was older than 67 years in 2016 (Federaal Planbureau, 2017). It is expected that this will increase to 22.5% in 2060. Belgium is as a

federal state subdivided in the Flemish region, the Walloon region and the Brussels-Capital region. The Flemish region is the most populated and with 17.3% being 67 years or older in 2016 and an expectation of 24% in 2060, it is and will be the oldest region. Compared to the Flemish region, the population of the Brussels-Capital region is much younger. Only 11.6% was older than 67 years in 2016. In 2060, the population over 67 years is expected to be 14.4 % (Federaal Planbureau, 2017). The relatively larger share of younger age group can be an explanation for the low percentage of older adults in this region (Smetcoren et al., 2018). The Walloon region had an older population of 15.5% in 2016 with an expectation of 22.7% in 2060 (Federaal Planbureau, 2017).

3 MORE LIFE TO YEARS

These extra years to life and the accompanying demographic shifts have profound implications for the society we live in and each individual. If older adults experience the added years in life in good well-being where they can enjoy their retirement, they can do the things they value and contribute to society in numerous ways, such as caring for a relative in their family, volunteering, or more. However, when the gained years are overshadowed by functional or mental decline, ageing is more perceived as challenges for older adults themselves and the society they live in (World Health Organziation [WHO], 2015). Older adults for example face more physical problems such as heart disease, stroke, cancer which prevalence all increased since the 1970s (Crimmins, 2015). There is a societal concern that an ageing population will increase healthcare expenditure and to be a substantial problem for public service provision (Howdon & Rice, 2018). Therefore, many health improvement programs and policies follow the in 1980 introduced *Compression of Morbidity hypothesis*. In this hypothesis, the emergence and increase of comorbidities should be compressed prior to one's death to reduce illness burden over a longer time period and to decrease healthcare costs (figure 1.1) (Fries, Green, & Levine, 1989; Fries, 2000). Additionally, in geriatric medicine, maintaining and improving the quality of life of older adults is a crucial target (or should be) (Lapid et al., 2011). Already since 1955, the Gerontological Society of America (GSA) accentuate this quality of life and well-being in their motto and called for "adding life to years, not just more years to life" (Baltes & Baltes, 1993).

Figure 1.1: Compression of Morbidity hypothesis



Source: Fries, Green, & Levine, 1989 – The future of population health is dependent upon relative movement of the two arrows, the first representing the average age of initial onset of disease or infirmity and the second representing average age at death. If the first moves more rapidly than the second, there is compression of morbidity.

4 RESEARCH ON AGEING

There are several academic disciplines conducting research on ageing or older adults. Geriatrics and gerontology are two of them that specifically focus on older adults. Geriatrics is the branch of medicine that is specialised in "the health and illnesses of older age and their appropriate care and services" (WHO, 2015, p. 227). The field of gerontology has a lot in common with geriatrics but is not a field of medicine. The research field of gerontology focuses on the "social, psychological and biological aspects of ageing" (WHO, 2015, p. 227). Gerontology is characterised by different disciplines and professions and aims to bridge between the academic fields of medicine, social and life sciences and studies the "ageing individual within a larger societal context" (Bass, 2009, p349). This PhD researches multiple aspects of ageing. The emphasis however, is on the social living environment of older adults and consequently insights of social gerontology theory and environmental gerontology theory are used in most chapters of this study. In an attempt to explain why certain phenomena occur in the ageing process, gerontologists use different theories "to guide research questions and hypotheses, to help explain research findings, and to inform interventions to solve ageing-related problems" (Alley, Putney, Rice, & Bengtson, 2010, p. 583).

The body of gerontological theories is large and addressing all of these theories, notwithstanding discussing them, would be a mammoth task. To give an insight in environmental and social gerontology theory, the next paragraphs give attention to three major person-environment approaches within Environmental Gerontology and to two major social gerontology theories (i.e. the macro perspective of Critical Gerontology and the micro perspective of Postmodern Gerontology).

Environmental Gerontology studies endeavours to explain, describe, modify or optimize the relationship between older adults and their socio-spatial surrounding (Wahl & Weisman, 2003). These studies focus on the theoretical understanding of person-environment relations in the ageing process. Three person-environment relations are modelled. First, in the *press-competence* model, the major assumption is that a low 'competence' (e.g. physical or cognitive decline) in combination with a strong 'environmental press' (e.g. neighbourhood deprivation) negatively impacts the behavior and the well-being of older adults. Second, in the *person-environment fit* model, the assumption is that the behaviour and well-being is affected by a discrepancy in the relationship between personal needs and environmental options. Imbalances in basic needs such as safety will result in lower behavioural autonomy, while an imbalance in the higher order needs such as esteem and self-realisation results in lower well-being. Third, in the *person-environment stress* model, the assumption is that environmental conditions due to the built environment can be stress-evoking. Within Environmental gerontology, there is a consensus that the physical environment and the social environment are interwoven but often researched separately and future research should simultaneously analyse both domains (Peace, Wahl, Mollenkopf, & Oswald, 2007).

Critical gerontology endeavours to connect later life events to larger social forces (e.g. governmental policy and international globalisation) (Estes, 1999, in Bass, 2009, p. 356). In the work of critical gerontologists, the emphasis is on the critical reflection about the declining (financial) commitment of policy towards the public by displacing the responsibility and risks to the individual (Dillaway & Byrnes, 2009). This line of thinking arguments that the current shift of social responsibility creates more inequity for vulnerable older adults and their families. In contrast to these macro frameworks,

postmodern gerontologists criticise that the ideas of critical gerontology are no longer relevant in a changed society. The industrial economy mass production world from the past changed towards a more customised serviced world we live in today. The focus of the postmodern gerontologist is to describe the changing world where older adults have now the opportunity of choices which are influenced by marketing and consumption. Their interest is to describe how these changes influence the experience of ageing (Bass, 2009).

As an early career researcher, I enjoyed reading several insights in social gerontology theory and I find it hard to embrace one single perspective. While reading books and papers on theory, more than once I came across the expression that a unified theory in social gerontology is the "holy grail" (e.g., Bass, 2006; Samanta, 2017). The fact that a single theory in social gerontology is non-existent presents an opportunity to work with different theories. This PhD dissertation's focus is on the well-being and social environment of frail older adults. Opposing to ignore the societal context of ageing individuals, also known as the microfication of gerontology (Hagestad & Dannefer, 2001), person-environment relations with a strong focus on *the social living environment* of older adults are included here in an attempt to add knowledge to the research field of environmental gerontology.

This PhD study did not focus exclusively on one theory. Most of the studies were designed to find answers on practical situations or dilemma's in society, rather than to conduct theoretical research. However, theories discussed above and other [e.g. Bronfenbrenner's ecological systems theory (1994) or Tornstam's gerotranscendence theory (1989)] were used in certain studies and these are discussed in detail within these chapters.

5 POLICY ON AGEING

5.1 Local level

While policy on ageing in Belgium is a jurisdiction of the regions (see 4.2), every local municipality is responsible to stimulate participation of older adults in local policy (Verté, De Witte & De Donder, 2007). The Flemish Decree for *stimulation of an inclusive Flemish policy for older adults and the policy participation of older adults* was approved on 21 April 2004 and municipalities developed their inclusive local senior policy plan. The Decree aims

to stimulate the political participation of older adults in policy (De Donder et al., 2014). Many municipalities have a senior advice committee who advice the local policy systematically on topics as educational, recreative activities or advocacy. According to recent data of the Flemish Council of the Elderly (Vlaamse Ouderenraad) which is the official advisory body for the Flemish policy on ageing, the advice committees are frequently asked for advice (47%) and more than half takes the initiative to advice the local government themselves (Denayer, 2018).

5.2 Regional level

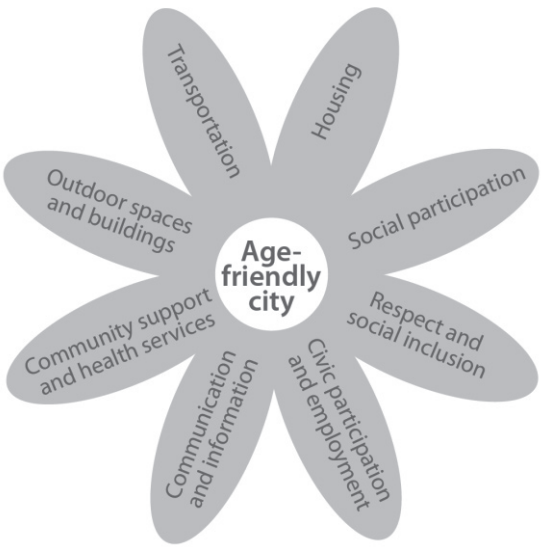
On the regional level, ageing policy is part of The Department of Welfare, Public Health and Family of the Flemish Government and with the consultation of the Flemish Council of the Elderly, four subjects of societal importance were selected for the term 2015-2020. These subjects are Prevention, Participation, Housing and Care (Vandeurzen, 2016) and are also included in the D-SCOPE project as research topics (see Chapter 2). The policy plan of the Flemish Government aspires to stimulate the participation and development of all older adults and is based on "trust in the competences of older adults and beliefs in the power of older adults in their social context" (Vandeurzen, 2016, p. 8). This PhD study translated this social context throughout its different chapters into *the social environment* or *the social living environment*.

5.3 International level

Both the local policy as the regional policy have adopted international trends that are also present in ageing research such as active ageing and healthy ageing, age-friendliness, ageing in place and community care. In a response of the ageing population worldwide, the WHO launched *active ageing* as a policy framework in 2002. To preserve the image of ageing as a positive experience, WHO defined active ageing as "the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age." (World Health Organziation, 2002, p. 12). Since 2015, the WHO has replaced the concept of active ageing with that of *healthy ageing* as the basis for the lead policy framework (Beard et al., 2016). This framework builds further upon the 2002 active ageing framework, emphasizing maintenance of high functional ability in later life. The new framework has been advanced taking into consideration functional ability and intrinsic capacity, which vary over the life course (WHO, 2015).

Age-Friendly Cities and Communities (AFCCs) are a strategy that has been promoted by the WHO to achieve active ageing (WHO, 2007). The strategy of age-friendliness was originally developed for city policies but later adapted into age-friendly community initiatives in more rural places (Menec et al., 2014). Although AFCCs initiatives are primarily targeted towards older adults, the concept includes all ages and is meant to be more than just elder-friendly (Fitzgerald & Caro, 2014). Improvement of the physical environment, for example, also benefits less mobile people, and secure environments stimulate children to participate in activities in their neighborhood (WHO, 2007). Using data from 158 focus groups in 33 cities with persons aged 60 years and older (n=1485) from lower- and middle-income areas, eight themes emerged housing, social participation, respect and social inclusion, civic participation, communication and information, community support and health services, outdoor spaces and building and transportation (figure 1.2) (Plouffe & Kalache, 2010). These themes are frequently used in scientific research (e.g. Smetcoren et al., 2018; Van Dijk, Cramm, Van Exel, & Nieboer, 2015), and the development of local policy (De Donder et al., 2014). The AFCCs concept or age friendly strategies are used in chapter 6, 7, 8 and 9 of this PhD-dissertation.

Figure 1.2 AFCCs topic areas



Source: WHO 2007

Another concept which is often returning in gerontological research and policies on ageing is *ageing in place*. The ageing in place concept refers to the idea that most older people prefer to stay in their local community as long as possible (Björnsdóttir, Ceci, & Purkis, 2015; Fänge, Oswald, & Clemson, 2012). This remains the case when they become frail and have increasing care and support needs (Wiles, Leibing, Guberman, Reeve, & Allen, 2011). When older adults leave their homes, the influence is large on their happiness, feelings of loneliness and even their quality of life and health (Schorr & Khalaila, 2018). In policy, the focus of ageing in place is mainly on an age friendly built environment and actions for affordable housing in later life. Providing care at the places where people live rather than institutionalization, whether or not in combination with community care (see further) has lately gained more and more attention. To achieve more ageing in place, local policies exercise with several approaches for community-based care are such as case-management and home-visits. (WHO, 2015).

Recently, the concept of ageing in place was extended to ageing *well* in the *right* place. There are boundaries to ageing in place and in certain cases, the cost of ageing in place is higher than moving to a place that caters their needs without leaving the community (De Donder et al., 2017). Ageing in the right place refers to continuing to live in the same home yet also moving to a home that is more adapted to their needs while maintaining vital connections with their community, friends, and family (Beard et al., 2016; WHO, 2015). As older adults stress the importance of well-being in their life, especially when being frail and care dependent, the concept can be further extended to ageing *well* in the *right* place. More information on this topic is discussed in chapter 3, 6 and 8 of this dissertation.

A last trend in research and ageing policy in this study is *community care* which is in a way related to ageing in place. When care dependent older adults age in place, they preferably receive their care by informal caregivers (Eckert, Morgan, & Swamy, 2004). Long-term care at home is often only achievable when help from relatives or neighbours is additional to formal care (Koops & Kwekkeboom, 2005). This community care receives more attention from policy makers as to constrain public sector spending (Keating, Otfinowski, Wenger, Fast, & Derksen, 2003). Recent research indicates that informal care can act as substitute

for formal home care. When older adults become frail however, it should be noted that the substitute relationship turns into a complementary relationship (Lambotte et al., 2018).

6 FRAILTY IN LATER LIFE

6.1 Conceptualisation and operationalisation of frailty

Conceptualisation is a process of defining or clarifying meaning of the terms used in a study. The issue in frailty research is that there is no consensus on the conceptualisation (Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010) nor the operationalisation of what frailty actually is (Dent, Kowal, & Hoogendijk, 2016). An early definition in 1978 by Federal Council on Aging in the United States, describes frailty as "persons, usually but not always, over the age of 75, who because of an accumulation of various continuing problems often require one or several supportive services in order to cope with daily live" (Federal Council on Aging, 1978, p. 1). But afterwards different researchers used different definitions resulting in a multitude of definitions, which at their end result in different operationalisations (De Witte et al., 2013a) Besides different conceptualisations, researchers agree there is a considerable heterogeneity in the group of older people identified as frail (Looman et al., 2018). In response to both issues, according to De Witte et al. (2013a) four types of conceptualisations can be distinguished: (a) biomedical, (b) bio-psychological, (c) bio-psycho-sociological and (d) integrative conceptualisations and all use different measurements for assessing frailty. The examples given below illustrate only a small number of instruments, however, to provide sufficient insight, the most common instruments are addressed.

Most attention is given to the biomedical conceptualisations of frailty where "geriatricians define frailty as a biologic syndrome of decreased reserve and resistance to stressors, resulting from cumulative declines across multiple physiologic systems, and causing vulnerability to adverse outcomes" (Fried et al., 2001, p. 146). This conceptualisation is the most used in scientific *clinical* research (Bouillon et al., 2013) and is evaluated with weight loss, weakness, self-report of exhaustion, slowness and low physical activity (Fried et al., 2001). In the bio-psychological conceptualisation, static as well as dynamic frailty markers were used for physical (e.g. body weight) and psychological (e.g. cognitive functioning) frailty markers (Puts, Lips, & Deeg, 2005). For the bio-psycho-sociological

conceptualization, the Frailty Index of Accumulative Deficits (FI AD) (Mitnitski, Mogilner, & Rockwood, 2001) accumulate 30 or more deficits in health such as help with activities of daily living (ADL), social support, illnesses (e.g. high blood pressure, heart attack and stroke) cognitive functioning (Mini Mental State Examination) or other physical aspects (e.g. Body Mass Index, grip strength and pace). This index can be used in large data samples on health in later life (e.g. Survey of Health, Ageing and Retirement [SHARE] study in Europe) (Searle, Mitnitski, Gahbauer, Gill, & Rockwood, 2008). The Edmonton Frail Scale (Rolfson, Majumdar, Tsuyuki, Tahir, & Rockwood, 2006) is shorter than the FI AD and uses 9 components similar to the FI AD and is intended to identify frailty in clinical populations (Dent, Kowal, & Hoogendijk, 2016).

These different approaches of frailty are frequently criticized as being too negative and having a stereotypical image of ageing (Markle-Reid & Browne, 2003). As a response to this criticism, several integrative conceptual models for multidimensional frailty were developed. In a new definition, based on existing conceptual definitions, frailty is characterised as "a dynamic state affecting an individual who experiences losses in one or more domains of human functioning, which is caused by the influence of a range of variables and which increases the risk of adverse outcomes (Gobbens, et al., 2010, p. 342). Examples are the Tilburg Frailty Indicator (TFI) which includes a physical, a psychological and a social domain (Gobbens, van Assen, Luijkx, Wijnen-Sponselee, & Schols, 2010). In the Groningen Frailty Indicator (GFI), also the cognitive domain is included (Steverink, Slaets, Schuurmans, & van Lis, 2001). A last example of a multidimensional frailty measurement is the Comprehensive Frailty Assessment Instrument (CFAI). This self-administered instrument measures four subscales or domains of frailty: physical, social, psychological and environmental frailty. This instrument and was developed with data of the Belgian Ageing Studies (BAS). The physical domain assesses general physical health (four items, e.g., bending or lifting); the psychological domain evaluates emotional loneliness (three items, e.g. I miss having people around me) and mood-disorders (five items, e.g., unable to cope with problems). The social domain includes social loneliness (three items, e.g., there are plenty of people I can lean on when I have problems) and social support (three groups of social support networks). The environmental

domain was captured by measuring conditions of housing problems (five items, e.g., my house is not comfortable) CFAI and (De Witte et al., 2013b).

Within de D-SCOPE project (see chapter 2), the CFAI was used in the first phase of the project. In the second and third phase of this project, the CFAI-plus was used. The latter instrument was developed within the project and added subjective cognitive frailty as a fifth frailty domain evaluates cognitive functioning (four items, e.g., I have trouble with following a story in a book or on TV) (De Roeck et al., 2018). To date, the CFAI-plus is the only frailty assessment instrument that includes 5 dimensions of frailty. The complete CFAI-plus can be seen in appendix 3. Throughout this dissertation, frailty is addressed as a multidimensional construct unless emphasized otherwise, for instance when the focus in international literature was primarily on *physical* frailty, or on *social* frailty in chapter 4.

6.2 Frailty outcomes

Research indicates that physical frailty in later life is a better predictor for mortality than chronological age (Song, Mitnitski, & Rockwood, 2010). Other so-called adverse outcomes that often emerge in frailty research are hospitalisation, institutionalisation, ADL disabillity, falls, fractures and more (Vermeiren et al., 2016). In line with the earlier mentioned 'ageing in place' discours, governments search for strategies or interventions to help older people to stay at home in order to prevent or delay high costs of institutionalisation (Scharlach, 2011).

In the same line of reasoning, the purpose of our D-SCOPE project was to prevent multidimensional frailty or worsening of frailty to detect frail community-dwelling older adults and to improve their access to care and support (see chapter 2). Within D-SCOPE, outcomes of frailty are not solely situated on adversities or negativities. Including more positive frailty outcomes such as quality of life and/or psychological well-being (e.g. Clegg et al., 2014; Dury et al., 2017; Landi et al., 2017; van der Vorst et al., 2017; Walters et al., 2017), meaning in life and sense of mastery (Dury et al., 2018; van der Vorst et al., 2017) were before the D-SCOPE study only rarely studied and have a major role in this dissertation. More information about this topic is presented in chapter 3, 4, 5 and 8.

7 Detection and prevention of frailty

In order to prevent adverse outcomes by providing appropriate support, it is a challenge to detect frailty in an early state (De Witte et al., 2013a). There are several intervention programs that target physical frailty and unmet medical needs (Marzetti et al., 2015). Multidimensional frailty in mind, there are numerous other needs which are relevant to include for detection. At the moment community-dwelling older adults experience difficulties or become more frail, most of them can rely on the alertness of family or relatives in guiding them towards the right care. General practitioners and other care providers are key figures in the timely detection of problems that arise steadily or urgently (Lette, Baan, van den Berg, & de Bruin, 2015). Nonetheless, 3.8% of the community dwelling older adults in Flanders in need for care has a care shortage and are withhold from the care they need (Fret et al., 2017). Tragic stories headlined the newspapers in the summer of 2017 when three people were found dead in the city of Bruges in the same week. These citizens passed away long before their bodies were found (Standaard, 2 augustus 2017). To detect frail older adults in the community who stay below the radar, cities and communities can use the D-SCOPE strategy (see chapter 2) as an outreaching strategy in the detection for multidimensional frailty. With the expectation that some people are reluctant towards such intervention and refuse help (Lange, 2014; Geelen & Aarnoudse, 2011), other people who stand close to them might offer possibilities in guiding them to towards care. The possibility for detection by professionals such as local business owners is explored in chapter 9.

8 Longevity and frailty

This chapter started with the aspiration for more quality of life in later life by adding more life to years instead of years to life. With the early detection of frailty, levels of physical frailty can be reduced (Puts et al., 2017) or unnecessary adverse outcomes can be prevented (De Witte, Hoeyberghs, De Donder, Verté & Schols, 2015). Earlier was mentioned that frailty is a dynamic state (Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010). Research on physical frailty indicates that it is a manageable condition (Shaw et al., 2018) and reversible in an early stage (Rodriguez-Mañas & Fried, 2015). However, for older adults in a later stage of physical frailty, only a small group can benefit from multidomain interventions that focus on physical exercise and nutrition which are needed

to reverse physical frailty (Tarazona-Santabalbina et al., 2016). This implies that apart from much needed stimulation for exercise and a healthy lifestyle in old age, physical frailty cannot be eliminated.

In multidimensional frailty, there are multiple interacting factors expressing (a) the complex relationship between the dimensions of frailty and (b) the relationship between these dimensions and the resources/abilities frail older adults have (e.g. Rockwood, Fox, Stolee, Robertson, & Beattie, 1994). Within the *gerodynamic model*, Sipsma (1993) called for attention to understand the *balance* between on losses and deficits on the one side and support and autonomy on the other side. In this line of reasoning, two individuals with the same level of frailty can have a different frailty balance because of different support they receive (de Blok, Meijboom, Luijkx, & Schols, 2009). The D-SCOPE project (see chapter 2) researched a range of balancing factors for frailty in later life. The role of the social environment as a balancing factor for frailty and frailty outcomes was one of the key research aims within this dissertation.

9 Research aims

The main research aims of this PhD study are twofold. First, the focus is on positive frailty outcomes. Frail older adults experience a sense of well-being despite being frail and the inclusion of positive outcomes is under researched in frailty studies. To address this research gap, the first research aim is to gain more knowledge on positive frailty outcomes. The second aim is directed towards the relationship between the social environment and frailty in later life. This research aim stems from the current policy direction that acknowledges the social context of older adults as a powerful context. Just as the previous research aim, this topic too is poorly addressed in scientific research. In the second and third part of this thesis, both research aims were further given attention by means of various specific research aims in the studies that delineate this thesis.

9.1 Research aims on positive frailty outcomes:

Study 1: To research how frail community-dwelling older adults experience their frailty and their well-being. Also, to explore which factors ensure positive well-being for frail older adults in a guaranteed 24h care at home project (Zorg24).

Study 2: To focus on one domain of well-being by researching the experience of meaning in life as well as the loss of meaning for socially frail older adults.

Study 3: To develop a short well-being instrument for older adults (SWIO).

9.2 Research aims on the relationship between the social environment and frailty in later life:

Study 4: To investigate whether the social environment increases the risk of frailty or helps to prevent it.

Study 5: To gain insight how frail older adults socially participate in the society. Also, to research which factors influence frail older people's social participation and the role of the social environment in this process.

Study 6: To research if the social environment is a balancing factor for frailty outcomes.

Study 7: To explore the possibility of antenna professions in the detection of frail community dwelling older adults.

10 DISSERTATION STRUCTURE

To achieve the research aims in this thesis, several studies were completed. Table 1.1 presents an overview of the chapters, the research aims, the study design, the data collection and the publication status.

Table 1.1: Overview of the studies

	Research aim	Study design	Data	Publication status
Chapter 3	To research how frail community-dwelling older adults experience their frailty and their well-being. Also, to explore which factors ensure positive well-being for frail older adults in a guaranteed 24h care at home project	Mixed method	18 older adults with a high care profile	Published in Verpleegkunde (2 June 2018)
Chapter 4	To focus on one domain of well-being by researching the experience of meaning in life as well as the loss of meaning for socially frail older adults	Qualitative interviews	56 socially frail older adults	Submitted in Journal of Community Health Nursing (30 September 2018)
Chapter 5	To develop a short well-being instrument for older adults	Cross-sectional	871 older adults with a frailty risk profile	Submitted in *International Psychogeriatrics* (30 Augustus 2018) – under review
Chapter 6	To investigate whether the social environment increases the risk of frailty or helps to prevent it	Systematic review	Existing studies	Accepted for publication in *Journal of Applied Gerontology* (17 December 2016)
Chapter 7	To gain insight how frail older adults socially participate in the society. Also, to research which factors influence frail older people's social participation and the role of the social environment in this process	Qualitative interviews	38 very frail older adults	Submitted in *Journal of Gerontology: Social Sciences* (9 July 2018) – under 2nd review
Chapter 8	To research if the social environment is a balancing factor for frailty outcomes	Cross-sectional	869 older adults with a frailty risk profile	
Chapter 9	To explore the possibility of antenna professions in the detection of frail community-dwelling older adults	Qualitative focusgroups and interviews	18 non-care professionals	Submitted in *Journal of Social Intervention: Theory and Practice* (23 September 2018)

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CHAPTER 2

D-SCOPE: DETECTION, SUPPORT AND CARE FOR OLDER PEOPLE: PREVENTION AND EMPOWERMENT

Excerpted and modified from 4 co-authored publications:

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

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1 Abstract

The purpose of this chapter is to provide the reader with the rationale of the Detection, Support and Care for Older People: Prevention and Empowerment (D-SCOPE) research project, a description of the methodology that was used to gather data for the studies presented in this PhD study and a brief overview of the partners of D-SCOPE.

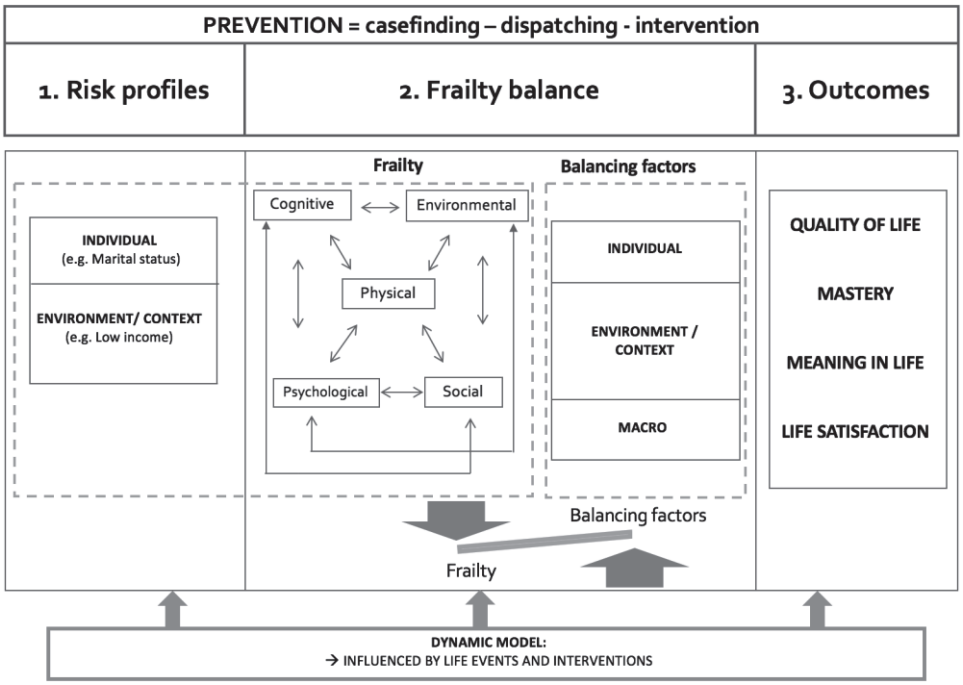
2 Introduction

From January 2015 until December 2018, 21 researchers from the Vrije Universiteit Brussel, the University of Antwerp, University College Ghent, the Catholic University of Leuven (Belgium) and Maastricht University (the Netherlands) collaborated on the D-SCOPE project. The D-SCOPE project was granted as an SBO-project (Strategisch Basis Onderzoek). Within this type of research, results have to serve prospective economic or social applications in the matter of new products, processes or services. The team of researchers consists of 12 professors, 2 postdoctoral and 7 predoctoral researchers.

The project started from the observation that frailty in older adults is often not detected on time. When problems and needs of older adults are not recognised or treated in time, this results in a decline of their autonomy and quality of life. Existing initiatives to proactively detect multiple problems in frail older adults insufficiently address the needs of these people. (Lette, Baan, van den Berg, & de Bruin, 2015). Prevention of frailty in older adults would benefit the older person, his environment and be more cost-effective for society. Accordingly, early detection of frailty in an older community-dwelling population and tailored care and support are important (Dury et al., 2017).

Within D-SCOPE, we accentuate the fact that ageing in general and frailty in particular does not necessarily has negative consequences in daily life when the right care and support is present. There is a need to take the strengths and resources of older adults into account besides measuring the deficits of frailty alone (Buntinx, Paquay, Fontaine, Ylieff, & De Lepeleire, 2004). Therefore, D-SCOPE prefers the terms balancing factors and frailty balance. The main research aims of the research consortium were (1) to identify strategies for proactive detection community-dwelling older adults at risk of frailty; and (2) to guide them towards appropriate support and/or care with a strong focus on empowerment and (3) to develop a frailty balance instrument.

Figure 2.1 Overall conceptual model of the D-SCOPE project



3 Methods

The 4-year research project was divided in three (chronological) phases.

Phase 1: identifying frailty risk profiles of home-dwelling older adults

In order to prevent or delay frailty, D-SCOPE developed frailty risk profiles to identify the older adults in the population who have the highest risk for frailty in order to provide accurate case-finding. In a study of Dury et al. (2017), these risk profiles in terms of sociodemographic characteristics and socioeconomic status were identified in a sample of home-dwelling older adults (n = 28 049). In this study frailty was measured with the Comprehensive Frailty Assessment Instrument (CFAI) which measures four domains of frailty (physical, psychological, social and environmental) and total frailty. The CFAI is a validated instrument and is proved to be internally consistent with a Cronbach's α of 0,812 (De Witte et al., 2013a, 2013b). The sociodemographic characteristics were gender, marital status, moved in the previous 10 years and country of birth and for socioeconomic status, education and household income was used. Results show that risk profiles differ

over different frailty domains. Older adults are higher at risk for physical frailty when they are older, however, this risk profile is absent for the other domains of frailty. Another example is a higher risk for social frailty for unmarried older adults, and higher risks for psychological and environmental frailty when older adults are lower educated or have lower household incomes. All results are available in the study of Dury et al. (2017).

Phase 2: identifying balancing factors in frail older adults

To explore how frail older adults perceive their frailty, quality of life, sense of mastery, meaning in life, and care and support, a mixed method study was conducted in a sample of 121 home-dwelling older adults. Each older person participated in a questionnaire including the CFAI and the Montreal Cognitive Assessment tool (MoCA), a screening tool to detect mild cognitive impairment. The quantitative part was followed by a semi-structured interview. Findings of this study resulted in the development of the CFAI-plus (De Roeck et al., 2018) and in a number of papers by D-SCOPE researchers. Worthy to know is that participants for this study were not only found by the researchers of D-SCOPE, but also with care organisations and partners of D-SCOPE such as Focus Plus vzw, Ageing In Place Aalst (AIPA), Zorg24, servicecentre Harmonie in Brussel and more. The complete study methodology of phase 2 can be found in Dury et al. (2018).

Chapter 4 and 7 of this Phd make use of these phase 2 – data.

Chapter 3 in this PhD study focusses specifically on the data from participants of the Zorg24 project.

Phase 3: a focus on prevention

By combining the risk profiles from phase 1 and the identified balancing factors from phase 2, a randomised controlled trial was carried out in three Flemish municipalities: Knokke-Heist, Gent and Tienen. The objectives were to detect frail community-dwelling older adults who would have remain undetected without the D-SCOPE project, to guide those who are frail towards appropriate care and support, to prevent that care and support is discontinued and to improve the frailty-balance during 6 months. 869 older adults completed a survey at baseline and 570 participated in the follow-up study. The complete protocol is available in the study of Lambotte et al. (2018).

Chapter 5 and 8 of this Phd use phase 3 data.

Other

During phase 3, interviews were held with non-care professionals who are frequently in contact with possible frail older adults. A separate study explored how they could recognise undetected frail older adults and what their opinion was on being a link between the older adult and care organisations.

This study is presented in chapter 9.

To identify the relationship between frailty and the social environment, a systematic literature review was performed on existing studies on the subject. Four databases (Web of Science, Proquest Social Science, Pubmed and Ovid PsycINFO) were searched for relevant articles, using advanced search strategies.

This study is presented in chapter 6

4 References

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Van: "[redacted]om>
Aan: "[redacted]@knokke-heist.be>
Verzonden: Woensdag 13 septe[redacted]
Onderwerp: huisbezoek

Beste,

Hiermee deel ik u mee dat ik niet wens deel te nemen aan dit project.

Ik ben goed zelfstandig en heel sportief .

Dank voor de info .

mvg
[redacted]
[redacted]
heist aan zee

Van: "[redacted]mail.com>
Aan: "[redacted]-heist.be>
Verzonden: Woensdag 14 juni [redacted]
Onderwerp: voorzieningen voor zorg en welzijn.

Goeie namiddag,

Eerst en vooral van harte dank voor jullie inzet naar het welzijn van de inwoners van Knokke-Heist ! Ik vind het een fantastisch initiatief.

Gelukkig ben ik persoonlijk nog fit en goed te been en heb ik dus jullie hulp nog niet nodig !

Fijne dag verder, Met beleefde groeten,

[redacted]

Van: "[redacted]tmail.com>
Aan: "[redacted]@knokke-heist.be>
Verzonden: Dinsdag 13 juni [redacted]
Onderwerp: Bezoek Daan Duppen

Geachte Mevrouw,

Ik kan niet aanwezig zijn op de voorgestelde dag door de heer Duppen.
Ik kan ook geen andere afspraak maken daar ik door familiale omstandigheden niets op voorhand kan plannen.

Dank voor uw bezorgdheid. Ik ben echter zeer tevreden over het gemeentelijk beleid inzake senioren.

Met beleefde groeten,

[redacted]

PART II - A NEW APPROACH: RESEARCH ON POSITIVE FRAILTY OUTCOMES

Chapter 3

Ageing Well in Place: High Quality Living at Home with Guaranteed 24-hour Care

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This study (in Dutch) is published in:
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1 SAMENVATTING

Doel: Deze studie gaat na hoe thuiswonende kwetsbare ouderen hun kwetsbaarheid en hun welbevinden ervaren. Daarnaast tracht de studie een antwoord te vinden op de vraag welke factoren ervoor zorgen dat kwetsbare ouderen een positief welbevinden hebben binnen een project met 24 uurs zorggarantie aan huis (Zorg24).

Methode: Kwalitatieve studie met thematische analyse op interviews van 18 ouderen in het Zorg24 project (Gent, Tienen).

Resultaat: Ouderen ervaren kwetsbaarheid ruimer dan enkel fysiek. Zorgverleners ondersteunen hen bij verschillende vormen van kwetsbaarheid en verhogen hun welbevinden, waardoor zij kwaliteit in hun leven, zingeving, gevoel van regie over hun leven en betrokken te zijn in de samenleving (kunnen) ervaren. Respondenten vertellen dat hoe dankzij Zorg24 zij kwaliteitsvol thuis kunnen blijven wonen. Daarnaast tonen de resultaten enkele factoren die kwetsbaarheid balanceren bij de ouderen.

Discussie: Binnen het discours van vermaatschappelijking van de zorg kunnen kwetsbare ouderen dankzij een Zorg24-project niet enkel langer, maar ook kwaliteitsvol thuis blijven wonen. De discussie stelt zich echter ook de vraag naar de grenzen van de thuiszorg, en hoe lang we “langer thuis blijven wonen” moeten stimuleren.

Conclusie: Mede dankzij een 24uurs zorggarantie ervaren kwetsbare ouderen een goede kwaliteit van leven, zingeving, zelfregie en inclusie.

Trefwoorden: kwetsbaarheid, thuiswonende ouderen, welbevinden, kwaliteit van leven, kwalitatief onderzoek

2 INLEIDING

2.1 Ageing ‘well’ in place

In de toekomst zullen er meer ouderen in onze samenleving zijn en bijgevolg zullen er ook meer ouderen zijn die het risico lopen om kwetsbaar te worden. In 2016 was 16,1% van de Belgische bevolking ouder dan 67 jaar. Volgens schattingen zal dit percentage oplopen tot 22,1% in 2040 (Federaal Planbureau, 2017). In Nederland was 19% van de bevolking 65 jaar of ouder en loopt dit op tot 26% in 2040 (Stoeldraijer, van Duin, & Huisman, 2017). Over heel Europa (EU-28) wordt geschat dat 27% van de bevolking in 2040 65 jaar of ouder

zal zijn (Eurostat, 2017). Door een gelijklopende stijging in de vraag naar zorg en de druk die daarbij komt op de capaciteit en de financiering van zorgsystemen (Willemé, 2010) zien we enerzijds een groeiende focus op preventie van kwetsbaarheid en anderzijds een verschuiving naar meer vermaatschappelijking van de zorg. Dit fenomeen is niet alleen zichtbaar in België en Nederland, maar ook in andere Westerse landen.

Een zeer grote groep ouderen koestert de wens om oud te worden in de vertrouwde leefomgeving (Löfqvist et al., 2013; Smetcoren, 2016). Binnen internationale literatuur wordt de term 'ageing in place' gehanteerd om de tendens te omschrijven waarbij ouderen zo lang mogelijk thuis *willen* blijven wonen. Deze sterke verankering die ouderen ervaren met hun woonomgeving kent een aantal verklaringen. Een eerste vaststelling is dat bij het ouder worden, de mobiliteit en buitenhuisactiviteiten langzaam afnemen, waardoor men meer aangewezen is op de directe woonomgeving (Penninx & Royers, 2007). Naast het meer afhankelijk worden tot de woonomgeving, speelt ook de emotionele betrokkenheid tot deze omgeving een significante rol (Peace, Holland, & Kellaher, 2011; Smetcoren, 2016). Ouderen voelen zich vertrouwd met hun woning waar allerlei herinneringen aan vasthangen. Naast een wens van ouderen zelf is dit ook een beleidsideaal en krijgt het zowel op de Europese agenda als wereldwijd de nodige aandacht in de vorm van "vermaatschappelijking van de zorg", een term die we ondertussen al vele jaren horen klinken binnen het zorgbeleid. Doorheen de jaren evolueerde het principe van vermaatschappelijking van zorg *in* de samenleving naar zorg *door* de samenleving (De Donder et al., 2017), waarbij een sterke focus kwam te liggen op zelfzorg, mantelzorg, en zorg door vrijwilligers. De idee van ouderen die hun oude 'jaren' 'slijten' in een woonzorgcentrum is sterk achterhaald. Enerzijds daalt het aandeel ouderen met lichte zorg in de Vlaamse woonzorgcentra. Anderzijds stijgt het aandeel bewoners met een zwaardere zorgbehoefte (Agentschap Zorg en Gezondheid, 2017). In Nederland is er zelfs sprake van een daling van ouderen die verblijven in verzorgings- of verpleeghuizen (Solinge, 2015).

In vele Vlaamse woonkamers hangt de leuze 'Oost, west, thuis best', maar wanneer men zich in een kwetsbare situatie bevindt, kan dit 'best' in gedrang komen. Onverbiddelijk in een onaangepaste, kwetsbare omgeving blijven wonen, vormt een risico voor de gezondheid, de onafhankelijkheid en het welzijn van ouderen (Sixsmith & Sixsmith, 2008;

Wagner, Shubair, & Michalos, 2010) en kan aanleiding geven tot een vervroegde opname in een residentiële setting (Davey, de Joux, Nana, & Arcus, 2004). Een groeiend aantal kwetsbare ouderen dat thuisblijft, zal naast de zorg die verleend wordt door de omgeving dan ook een beroep doen op thuiszorgdiensten (Fret et al., 2017). Fysiek kwetsbare ouderen in België doen bijvoorbeeld beroep op maaltijden aan huis, gezinszorg en thuisverpleging in het bijzonder (Hoeck et al., 2012). Het aanbod van thuiszorgdiensten is echter sterk gefragmenteerd (Metzelthin et al., 2013) waardoor een integrale en gepersonaliseerde zorg vaak ontbreekt en dienstverleners nog te vaak binnen hun eigen organisatie werken (Nies, 2015). Recent onderzoek in Vlaanderen en Brussel toont aan dat professionals zelf aangeven dat zij eigenlijk meer met andere zorgorganisaties (zouden) moeten samenwerken om deze versnippering tegen te gaan (De Donder et al., 2017).

Gezien het aantal ouderen in Vlaanderen en Nederland nog zal groeien komende decennia, zal ook het aantal ouderen die zich in wetsbare situaties bevinden toenemen. Met de huidige beleidsfocus 'ouderen zo lang mogelijk thuis te laten wonen' is er aldus een grote nood aan alternatieve, innovatieve oplossingen opdat niet louter 'ageing in place' maar wel 'ageing *well* in place' kan gerealiseerd worden. Om hieraan tegemoet te komen, hebben verschillende actoren betrokken bij het 'wonen-welzijn-zorg'-verhaal van ouderen een belangrijke rol te vervullen. Daarbij dient ook zeker de stijgende multi-complexe kwetsbaarheid in acht genomen te worden. De verscheidenheid en hoeveelheid van vragen waar ouderen mee kampen, overstijgt soms de mogelijkheden van de huidige aanpak en organisatie van thuiszorgdiensten. De kwetsbaarheid en complexiteit zit meestal in de versnippering van de zorgorganisatie(s) en hun weinig flexibele werking dan in de persoon of diens situatie (De Donder et al., 2017). Een gerichte, flexibele aanpak op maat is nodig om tot ageing *well* in place te komen.

Een project met een meer flexibele aanpak is Zorg24. Dit zorg vernieuwend project valt onder het "Protocol 3 programma" waar zorgverleners in verschillende projecten strategieën die vernieuwend zijn voorstellen met als doel de autonomie van ouderen te ondersteunen en vroegtijdige opnames in residentiële voorzieningen te vermijden. Zorg24 ging van start te Gent in 2010, waarna Tienen/Hoegaarden en Oostende volgden in 2014.

Op 31 augustus 2018 lopen deze projecten ten einde. Door de samenwerking van verschillende zorgverleners wordt een netwerk van 24/24u zorg rondom thuiswonende ouderen opgebouwd. Een zorgcoach stelt een zorgpakket samen voor zwaar zorgbehoevenden waar geen klassieke thuiszorg meer mogelijk is (ZORG24, n.d.). Door te werken met verschillende aanbieders biedt Zorg24 op deze wijze een alternatief voor het gefragmenteerde zorglandschap.

2.2 Van kwetsbaarheid naar welbevinden

Om de voorgenoemde kwetsbaarheid te beschrijven of te meten worden talrijke definities en meetinstrumenten gehanteerd. Frailty is de meest voorkomende term in de Engelstalige literatuur maar tot op heden is er geen consensus over één conceptuele en operationele definitie ervan (Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010). Doorgaans beperkt de literatuur zich tot fysieke kwetsbaarheid, alhoewel er de laatste jaren steeds meer aandacht bij onderzoekers, beleidsmakers en professionals is om een multidimensionale benadering van kwetsbaarheid te gebruiken (De Witte et al., 2013a; Gobbens, Schols, & van Assen, 2017). In een multidimensionale benadering van kwetsbaarheid worden naast het fysieke domein ook psychische, cognitieve, sociale en recentelijk ook omgevingsaspecten meegenomen. Prevalentiecijfers voor Vlaanderen op basis van de ouderenbehoefteonderzoeken bij thuiswonende volwassenen van 60 jaar en ouder (n= 21 664) tonen aan dat 21,1% ernstig kwetsbaar is. Gekeken naar de verschillende domeinen wordt vastgesteld dat 20,1% sociaal kwetsbaar is, gevolgd door 15,1% fysiek, 8,6% psychisch en 14,6% op het omgevingsdomein (Smetcoren et al., 2017).

Er is in de literatuur ook bewijs dat kwetsbaarheid een significante invloed heeft op de zogenaamde *adverse outcomes* of negatieve gezondheidsuitkomsten zoals mortaliteit, een verlies in het uitvoeren van activiteiten in het dagelijks leven (ADL), hospitalisatie, institutionalisering, vallen, en meer (Vermeiren et al., 2016). Onderzoek naar andere en meer positieve uitkomstmaten zoals kwaliteit van leven is zeer beperkt (Kojima, Iliffe, Jivraj, & Walters, 2016). Daarnaast wordt het subjectieve gevoel van kwetsbaarheid zelden meegenomen in onderzoek en praktijk. Er is nochtans een groot verschil tussen door een meetinstrument als kwetsbaar geclassificeerd worden en zich kwetsbaar voelen (Grenier, 2006). Dit onderzoek tracht daarom naast het welbevinden van ouderen (kwaliteit van leven, zingeving, gevoel van inclusie en de regie over het eigen leven) ook subjectieve

kwetsbaarheid in kaart te brengen. We includeren zingeving omdat de ervaring van een zinvol leven op latere leeftijd voordelen heeft (Battersby & Phillips, 2016), regie omdat een hoger gevoel van controle over het eigen leven positieve effecten heeft bij ouderen en de negatieve effecten van kwetsbaarheid op functionele achteruitgang kan tegengaan (Lee, Chen, Peng, Chiou, & Chou, 2016). Als laatste nemen we ook inclusie mee omdat langer thuis blijven wonen niet altijd een garantie geeft op het bewaren van onafhankelijkheid en maatschappelijke inclusie. Het zijn net die zaken die belangrijk zijn voor 'ageing in place' (Barrett, Hale, & Gauld, 2012).

De vragen die we ons stelden in het onderzoek waren:

1) Hoe ervaren zogeheten kwetsbare ouderen zelf die kwetsbaarheid?
2) Hoe ervaren kwetsbare ouderen hun 'welbevinden'?
3) Welke factoren of randvoorwaarden zorgen ervoor dat kwetsbare ouderen een positief welbevinden hebben?

En doorheen die vragen willen we exploreren welke rol speelt het Zorg24 project bij het 'ageing *well* in place' speelt van kwetsbare ouderen?

3 Data en Methode

3.1 D-SCOPE-project

Het D-SCOPE-project staat voor Detection, Support and Care for older people – Prevention and Empowerment. D-SCOPE doet onderzoek naar: 1) gerichte, proactieve detectie van kwetsbare ouderen in hun lokale omgeving en 2) effectieve toeleiding naar de gepaste hulp en ondersteuning (D-SCOPE, n.d.). In dit project werd bij 121 thuiswonende ouderen aan de hand van een mixed-method studie nagegaan hoe ouderen kwetsbaarheid ervaren en hoe kwetsbaarheid een invloed heeft op hun kwaliteit van leven, zingeving en zelfregie. Er werd eveneens nagegaan welke balancerende factoren kwetsbaarheid beïnvloeden, of er scharniermomenten of transitiemomenten zijn die leiden tot kwetsbaarheid en of er een verschil is tussen objectieve kwetsbaarheid, gemeten met het Comprehensive Frailty Assessment Instrument (CFAI) en subjectieve kwetsbaarheid (De Witte et al., 2013b). Deelnemers werden (deels) gerekruteerd via de medewerkers van zorgorganisaties. 18

van de 121 respondenten waren cliënt van Zorg24, en deze vormen de focus van het voorliggende artikel.

3.2 Deelnemers

Alle deelnemers werden doelgericht geselecteerd en gescreend op in- en exclusiecriteria voor en tijdens het interview. Inclusiecriteria waren gebaseerd op risicoprofielen voor multidimensionele kwetsbaarheid zoals leeftijd, geslacht, burgerlijke staat, inkomen, opleiding en verhuisd zijn in de laatste tien jaar (Dury et al., 2018). Deelnemers werden geëxcludeerd in geval van hospitalisatie, wanneer de deelnemer onmogelijk de vragen kon beantwoorden volgens de interviewer of wanneer de gezondheidstoestand dermate slecht was volgens de deelnemer of diens mantelzorger. De interviews werden bij de oudere thuis afgenomen. Alle deelnemers werden voldoende ingelicht over de studie en tekenden een 'informed consent' voor deelname in hun voorkeurstaal. Om maximalisatie van deelnemers met een migratieachtergrond te bereiken werd een tolk voorzien voor zij die geen Nederlands of Frans spraken. De studie was geheel vrijwillig en deelnemers kregen geen vergoeding. Alle deelnemers werden bevraagd in de winter van 2015 – 2016.

Voor de voorliggende studie namen 8 ouderen deel die ondersteund werden door Zorg24 Tienen/Hoegaarden en 10 ouderen door Zorg24 Gent. Cliënten komen in aanmerking voor Zorg24 wanneer zij tot één van volgende categorieën behoren: een A, B of C profiel op de KATZ schaal, een B, C of Cd profiel op de residentiële KATZ schaal, de diagnose kregen van dementie vastgesteld door een geneesheer-geriater of een score van 6 of meer hebben op de Edmonton-schaal (voor het meten van kwetsbaarheid). Deze profielen of scores illustreren de zorgzwaarte van een persoon. Iemand met een B-profiel op de residentiële KATZ schaal bijvoorbeeld is fysiek afhankelijk om zich te wassen en te kleden en te verplaatsen of is gedesoriënteerd in tijd en ruimte en fysiek afhankelijk om zich te wassen en/of te kleden (RIZIV, 2018).

Tabel 3.1 geeft een overzicht van de kenmerken van de respondenten. 13 vrouwen en 5 mannen namen deel aan het interview. Hun gemiddelde leeftijd was 85,2 jaar. 1 oudere was gehuwd, de andere 17 ouderen alleenstaand (12 ouderen verweduwd, 2 gescheiden, 3 nooit gehuwd). Ook de domeinen van kwetsbaarheid zijn hierin opgenomen.

Tabel 3.1: karakteristieken van de deelnemers

Code	Leeftijd	Geslacht	Burgerlijke staat	Totaal	Fys	Omg	Psy	Soc	Cog
R1	92	V	Weduwe	**	**	*	**	-	-
R2	84	V	Weduwe	**	*	**	**	-	**
R3	90	M	Weduwnaar	-	-	*	-	*	*
R4	85	V	Gehuwd	**	*	*	*	*	**
R5	91	M	Nooit gehuwd	-	-	-	-	-	-
R6	85	V	Weduwe	**	**	*	**	*	**
R7[a]	74	V	Weduwe	*	-	*	-	*	*
R8	82	M	Gescheiden	**	**	*	*	*	**
R9	89	V	Nooit gehuwd	**	**	**	**	**	*
R10	95	V	Weduwe	*	**	-	-	-	-
R11	86	V	Weduwe	-	*	-	-	-	*
R12	79	V	Weduwe	*	**	*	*m*	-	-
R13	76	M	Nooit gehuwd	**	**	**	*	*	**
R14	89	M	Weduwnaar	-	-	-	-	-	*
R15	94	V	Weduwe	**	**	**	-	-	**
R16	87	V	Weduwe	*	**	-	-	-	*m*
R17	91	V	Weduwe	*m*	**	-	-	-	**
R18	66	V	Gescheiden	*m*	*m*	-	-	-	-

[a] = migratieachtergrond, Totaal = totaal kwetsbaar, Fys = fysiek kwetsbaar, Omg = Omgevingskwetsbaar, Psy = Psychisch kwetsbaar, Soc = sociaal kwetsbaar, Cog = cognitief kwetsbaar; ** = zeer kwetsbaar, * = matig kwetsbaar, - = niet/laag kwetsbaar , *m* = missing

3.3 Onderzoeksdesign

De overkoepelende studie bestond uit een vragenlijst met een kwantitatief luik, en een kwalitatief luik. In het kwantitatieve luik werd kwetsbaarheid gemeten aan de hand van de eerder genoemde CFAI. De CFAI kan drie niveaus identificeren: niet/laag, matig en ernstige kwetsbaarheid (De Witte et al., 2013b).

Hierna werd een kwalitatief interview afgenomen. We kozen voor kwalitatieve interviews om de ervaringen van thuiswonende ouderen met kwetsbaarheid te onderzoeken en volgden hierbij vier hoofdvragen: (a) “wat betekent kwetsbaarheid voor u en hoe ervaart u kwetsbaarheid bij uzelf?”; (b) “Heeft kwetsbaarheid volgens u een effect op een kwaliteitsvol en zinvol leven en in welke mate heeft u het gevoel dat u zelf beslissingen kan nemen over wat er in uw leven gebeurt?”; (c) “Wat moet een oudere doen om zijn of haar kwaliteit van leven te behouden als die kwetsbaar wordt?”; (d) “Wat waren de hoogtepunten en laagtepunten in uw leven gedurende het laatste jaar, kwamen er veranderingen voor in uw leven? En hoe kijkt u naar de toekomst?” Elk interview werd digitaal opgenomen en later verbatim getranscribeerd.
De interviews werden afgenomen door 6 onderzoekers na intensieve training met een ouder testpubliek. Deelnemers en onderzoekers kenden elkaar niet voor de aanvang van het interview. Elke deelnemer gaf geïnformeerde toestemming voor deelname, opname van het gesprek en een vertrouwelijke verwerking van de data voor wetenschappelijke doelen. De studie werd goedgekeurd door de ethische commissie van de Humane Wetenschappen van de Vrije Universiteit Brussel (ECHW_031).

3.4 Data-analyse

Kwantitatieve en kwalitatieve data werden apart geanalyseerd. Voor voorliggende studie werd enkel een beschrijvende kwantitatieve analyse gemaakt. Omwille van het lage aantal respondenten (N=121 in totaal, N=18 bij Zorg24) moeten de percentages met de nodige voorzichtigheid geïnterpreteerd worden. De kwantitatieve cijfers zijn beschrijvend, waarna de verhalen in diepte context geven aan de cijfers. Met behulp van de software MAXQDA werden de kwalitatieve interviews geanalyseerd volgens thematische content analyse. Hierbij werd een aangepaste versie van Qualitative Analysis Guide of Leuven (QUAGOL) gebruikt (Dierckx de Casterle, Gastmans, Bryon, & Denier, 2012). QUAGOL volgt een

voorbereiding op het coderingsproces alsook het eigenlijke coderingsproces. Om de interbeoordelaarsbetrouwbaarheid te verhogen werd elk interview een tweede maal geanalyseerd door een tweede onderzoeker uit het team. 82 verschillende labels werden door het researchteam ontwikkeld voor de 121 interviews. Voor meer informatie omtrent de analyse verwijzen we naar een meer uitgebreid artikel (Dury et al., 2018). Bij de analyse van de interviews werd gebruik gemaakt van citaten. Deze citaten zijn een letterlijke weergave van stukken uit de interviews, met de daarbij horende taalkundige foutjes en Vlaamse spreektaal en dienen ter illustratie of om de hoofdlijnen uit gesprekken kracht bij te zetten. Om de anonimiteit te garanderen van de respondenten geven we telkens een omschrijving van de persoon en niet hun naam.

4 RESULTATEN

4.1 Kwetsbaarheid

Tabel 3.2 geeft een overzicht van de kwetsbaarheidscijfers per domein. De data van de respondenten in deze studie (n = 18) worden ter illustratie vergeleken met de data van alle respondenten uit de D-SCOPE-studie (n = 121) en met data van een andere studie met een representatieve steekproef bij 60-plussers over Vlaamse gemeenten (n = 21.664) (Smetcoren et al., 2017). Procentueel zijn de respondenten in deze studie meer kwetsbaar op alle domeinen in vergelijking met Vlaamse cijfers met uitzondering van het sociale domein.

Tabel 3.2: Opdeling mate van kwetsbaarheid per kwetsbaarheidsdomein

Domeinen kwetsbaarheid		BAS (n = 21.664)	D-SCOPE (n = 121)	D-SCOPE ZORG24 (n = 18)
Fysieke kwetsbaarheid	Niet/laag	68,3%	39,5%	23,5%
	Matig	16,6%	32,8%	17,6%
	Hoog	15,1%	27,7%	58,8%
Psychische kwetsbaarheid	Niet/laag	64,7%	53,0%	55,6%
	Matig	26,7%	23,1%	22,2%
	Hoog	8,6%	23,9%	22,2%
Sociale kwetsbaarheid	Niet/laag	32,8%	53,3%	61,1%
	Matig	47,1%	32,5%	33,3%
	Hoog	20,1%	14,2%	5,6%
Omgevings-kwetsbaarheid	Niet/laag	54,8%	34,5%	38,9%
	Matig	30,6%	47,9%	38,9%
	Hoog	14,6%	17,6%	22,2%
Cognitieve kwetsbaarheid	Niet/laag	31,4%[1]	22,2%	29,4%
	Matig	28,7%[1]	23,9%	29,4%
	Hoog	39,9%[1]	53,8%	41,2%

[1] = Voor cognitieve kwetsbaarheid waren geen cijfers uit de Belgian Ageing Studies beschikbaar omdat die vragen niet zijn opgenomen in de BAS-vragenlijst. Om deze schatting te maken werd een specifieke sample gecreëerd in combinatie met data van Prof. Dierckx die zij apart verzamelde (n = 475).

Uit de kwalitatieve interviews met de 18 respondenten van Zorg24 bleek zeker de sterke aanwezigheid van fysieke kwetsbaarheid. Dit zorgde ervoor dat ouderen zich 'beperkt' voelden in hun dagelijkse leven. Daarnaast ervaarden ouderen kwetsbaarheid als een ruimer begrip dan enkel het fysieke domein. Zij vertelden over psychische, cognitieve, sociale en omgevingskwetsbaarheid. Bovendien ervaarden ouderen vaak niet één bepaalde vorm van kwetsbaarheid maar een samenspel van verschillende vormen.

> *Ik kan mij niet meer zo verdedigen, verbaal, ook in kracht, kwetsbaarder, ja. En ik heb ook meer zorg nodig dan je anders niet nodig hebt. Kwetsbaarder ja. (Man, weduwnaar, 90 jaar)*

Naast de vijf kwetsbaarheidsdomeinen die wij klassiek bestuderen binnen D-SCOPE, haalden de respondenten echter ook nog andere vormen van kwetsbaarheid aan. Zo spraken zij over financiële, digitale en administratieve kwetsbaarheid. Ook ageism en inclusie kwamen in de verhalen aan bod. Sommige ouderen gaven aan dat zij het gevoel hebben niet meer deel uit te maken van de samenleving, dat ze als kwetsbare en zorgbehoevende oudere genegeerd en gediscrimineerd worden, en voelden zich uitgesloten. Een vrouw had het over het betuttelen en niet met respect behandeld worden door zorgverstrekkers:

> *Dat je inderdaad fragieler wordt, in die zin dat de mensen u betuttelend behandelen. Dat vind ik een fragieler worden. Ze weten dat, het is een machtsverhouding. Het verzorgend personeel betuttelt u een beetje en behandelt u een beetje als een onnozel klein kind. En dat maakt dat je een gevoel zou kunnen hebben van kwetsbaarder te zijn... Pas op ik ben nog helder van geest. Men moet mij niet zo behandelen. (Vrouw, gescheiden, 66 jaar)*

Hierdoor hadden ze ook voor die verschillende vormen van kwetsbaarheid ondersteuning en zorg nodig, niet enkel voor dat fysieke. Zorgverleners gaven dat ook, buiten hun klassieke takenpakketten. Zo vertelde één respondent over een zorgverlener die voor de oudere achter een pita of frieten ging om de hoek en hoeveel dit voor de respondent betekende. Wat deze respondent dan weer als gemis aangaf, was dat deze met zijn emoties niet bij de zorgverstrekkers terecht kon. Een andere cliënt van Zorg24 gaf daarentegen net wel aan dat dit een sterkte was van 'de meiskes' (i.e. Zorg24):

> *Als ik het wat moeilijk heb dan schrei ik een keer, maar niet met mijn familie. Het is alleen een keer met de meiskes: ja dan zeg ik, ik heb het wat moeilijk vandaag. (Vrouw, weduwe, 87 jaar)*

Een andere respondent vertelde over samen met de zorgkundige te gaan roken. Ook al hoorde dit niet tot het specifieke takenpakket van de zorgkundige, was het wel belangrijk voor deze zorgvrager dat ook die 'zorg en ondersteuning' verleend werd. Opmerkelijk uit de kwalitatieve bevraging was dat hoe kwetsbaar ouderen volgens de CFAI ook waren, of hoe kwetsbaar ze zichzelf ook voelden, volgens hen waren andere leeftijdsgenoten vaak nog kwetsbaarder en slechter gesteld dan zij en daar trokken ze zich aan op.

4.2 Welbevinden

Ondanks de negatieve gevolgen die kwetsbaarheid kon hebben, gaven ouderen vaak aan dat zij een goede kwaliteit van leven, zingeving, zelfregie en gevoel van inclusie hebben, en kwaliteitsvol thuis konden blijven wonen. Kwetsbare ouderen gaven mee hoe belangrijk zij het vonden om hun levenskwaliteit, zelfregie, zingeving en gevoel van inclusie te behouden.

Zelfregie bijvoorbeeld omvatte verschillende aspecten volgens ouderen. Zo vertelden zij over het belang van eigenaarschap, namelijk de mogelijkheid om zelf keuzes te kunnen maken en autonoom te kunnen zijn. Ouderen spraken hierbinnen van eigen kracht. Dit hield het hebben van voldoende kennis, vaardigheden en zelfvertrouwen in om eigenaarschap te kunnen handhaven. Zo vertelde een oudere vrouw:

> *Ik ben het lijdend voorwerp niet. Ik ben, ik zou willen werkgever zijn van een aantal medewerkers: een poetsdame, mijn arts is daarbij, mijn kiné. Die maken eigenlijk een soort team rondom mij, en ik ben de dirigent. (Vrouw, gescheiden, 66 jaar).*

Zelfregie bleek ook geen zwart-wit verhaal. Ook kwetsbare ouderen, die heel zorgafhankelijk waren, bleven graag regie en autonomie behouden in verschillende fases van het zorgproces: van bij de nodendetectie, bij de zoektocht naar het beantwoorden van de zorgnood, bij het eigenlijke zorgen tot bij de evaluatie van die zorg. En Zorg24 zorgde volgens respondenten voor die zelfstandigheid.

Verschillende aspecten gaven zin aan/in het leven van kwetsbare ouderen zoals een doel hebben (vb. een feest zelfs in de verre toekomst of gewoon het huishouden doen), zich waardevol voelen (vb. familieproblemen kunnen oplossen, trots zijn op hun kapsel of mooie outfit) of verbinding (vb. met partner of vrienden of zelfs met de professionele zorgverstrekker). Dit konden grote bronnen van zingeving zijn (vb. gevoel van coherentie in het leven) of kleinere geneugten zoals deze vrouw getuigde:

> *Ik heb graag een babbel met iemand, met een potje koffie en een taartje, dat mag hè? (lacht). (Vrouw, weduwe, 86 jaar)*

Kwetsbare ouderen blijven het ook belangrijk vinden om betrokken te kunnen blijven in de samenleving, en dit op verschillende niveaus: familie, buurt, maatschappelijk, … Ouderen voelden zich verbonden in de samenleving door hun omgeving, lidmaatschap aan organisaties, … Ook de manier waarop de buurt was ingericht zorgde voor een gevoel van inclusie.

Een laatste belangrijke uitkomstmaat is kwaliteitsvol thuis wonen. Ouderen geven vaak aan zo lang mogelijk thuis te willen blijven wonen. Uit de interviews bleek dat kwetsbare ouderen evenwel aandacht hebben voor ouder worden in de juiste en aangepaste omgeving. Zo vertelden een aantal ouderen dat, indien zij niet langer op een goede manier thuis zouden kunnen blijven wonen, zij naar een andere woning, serviceflat of woonzorgcentrum zouden verhuizen. Vele respondenten vertelden dat Zorg24 ervoor zorgde dat zij langer thuis konden blijven wonen. Zonder ZORG24 zouden ze reeds verhuisd (moeten) zijn naar een woonzorgcentrum.
Belangrijk was daarbij de nachtzorg binnen Zorg24, wat thuis blijven wonen mogelijk maakte. Een mantelzorger die aanwezig was bij een interview vertelde:

> *Vroeger kwam de thuisverpleegkundige, maar de uren… Tja, nachtdienst, blijkbaar deed de thuisverpleegkundige dat niet… Ze zijn nochtans lang geweest.*

4.3 Balancerende factoren voor kwetsbaarheid

Tijdens de kwalitatieve interviews gaven kwetsbare ouderen een aantal balancerende factoren aan die ervoor zorgden dat zij kwaliteitsvol en autonoom konden leven, ondanks hun kwetsbaarheid. Deze balancerende factoren deelden we op in het individuele, het omgevings- en het macroniveau. Tot slot speelden ook kantelmomenten een rol in de kwetsbaarheidsbalans van ouderen.

Het individuele niveau bevatte ten eerste persoonlijkheidskenmerken, namelijk de manier waarop ouderen ingesteld waren en naar het leven keken. Daarbij hanteerden kwetsbare ouderen verschillende copingstrategieën om te kunnen omgaan met hun kwetsbaarheid. Het actief aanpakken van het probleem en optimisme waren vaak gebruikte copingstrategieën bij kwetsbare ouderen.

Het omgevingsniveau bevatte de buurt, sociale contacten en formele en informele zorg en ondersteuning. Op vlak van de buurt kwamen verhalen rond het hebben van voorzieningen in de nabijheid en het ontvangen van steun van buren. Uit de interviews bleek dat buren hulp gaven en ontvingen van elkaar, zelfs wanneer zij kwetsbaar waren. Vluchtige contacten met mensen uit de buurt werden als positief ervaren, op deze manier blijven zij verbonden met hun buurt. Daarnaast gaven heel wat ouderen aan dat het hebben van sociaal contact met familie, vrienden en buren erg belangrijk was, bijvoorbeeld om met hun problemen terecht te kunnen. Personen uit de omgeving zorgden voor minder gevoel van kwetsbaarheid door steun te bieden of ouderen te motiveren deel te nemen aan (sociale) activiteiten. Tot slot bleken formele en informele zorg belangrijke balancerende factoren. Naast de daadwerkelijke zorg en ondersteuning die ouderen kregen, benoemden zij ook het sociale aspect en welzijnsaspect als een belangrijke component, namelijk even kunnen ‘babbelen’ en afleiding hebben.

> *Ja, ik ben gelukkig als ik ze zie. Want ik beschouw die, ik zal ook nooit zeggen, een hulp. Nee, nee, dan zeg ik altijd mijn vriendin. En dan zijn ze fier. Ja. En één van die twee dus, van die twee goei, die heeft een auto. En, dan zegt ze: gij moogt mee gaan voor een boodschap te doen hé. Wij moeten dan wel natuurlijk*

iets betalen. Die is met mij een keer rondgereden. Dat was plezant hé. En dat is een heel lieve vrouw. Echt waar, echt waar, daar had ik geluk. Zo zijn er niet veel. (Vrouw, weduwe, 84 jaar)

Binnen het macroniveau kwam vooral de financiële betaalbaarheid, administratie en maatschappelijke evoluties aan bod. Ouderen werden vaak geconfronteerd met extra kosten omwille van medische/fysieke problemen. Ondanks terugbetaling van veel van deze kosten moesten ouderen zelf nog een deel van de kosten dragen. Ook administratie is voor een aantal kwetsbare ouderen een negatieve balancerende factor. Uit de interviews bleek dat sommige ouderen wel gebruik maakten van computers, maar vaak beperkt en met een welbepaald doel. Ouderen gaven dan ook aan dat ze moeite hebben om zich aan te passen aan vernieuwing zoals overschrijvingen via de computer, updates van websites waardoor alles er opnieuw anders uitziet etc.

Tot slot fungeerden kantel- en transitiemomenten als balancerende factor voor kwetsbare ouderen. Deze kantel- en transitiemomenten waren dynamisch en konden net zoals andere balancerende factoren positief of negatief ervaren worden. Ze waren vaak ook cumulatief, één kantelmoment kan een domino-effect in gang zetten. Tot slot konden kantel- en transitiemomenten gradueel of net plots plaatsvinden. Veranderingen in gezondheid, in dierbaren en in de woonsituatie zijn vaak genoemde kantelmomenten. Zo vertelde een oudere vrouw hoe het leven voor haar veranderd is sinds haar zoon recentelijk was verhuisd:

Het spijtige van de zaak is, daar heb ik wel spijt van, dat hij nu aan de kust gaan wonen is. Vroeger woonde hij in Tienen en hij werkte in Tienen. Als ik mijn kop uit het venster uitstak, dan zag ik hem voorbijrijden. Hij werkte hier en hij had zijn eigen auto. Hij moest dus de werken gaan controleren en dan was dat hier, dan was dat daar en dan kwam hij hier dikwijls voorbij. Soms kwam hij al een keer binnen. En euh, dat mis ik nu wel moet ik zeggen. (Vrouw, weduwe, 85 jaar)

Zorg24 was voor veel kwetsbare ouderen die hiervan hulp krijgen een zeer waardevolle vorm van ondersteuning. Zorg en ondersteuning 24/24 uur ervaarden ze net als dat stapje verder doordat ouderen hierop kunnen rekenen buiten de klassieke kantooruren wat een geruststellend gevoel gaf:

> *Die ziekte, dat kan optreden op iedere moment en dan zou ik hier dagen kunnen liggen als er niemand niet komt. En nu ben ik gerust, ze komen drie keer per dag kijken. Als ik wil komen ze ook 's nachts maar dat is nog niet nodig. En dat is een geruststelling. (Vrouw, weduwe, 85 jaar)*

5 Discussie

Dit onderzoek stelt 'ageing *well* in place' van kwetsbare ouderen centraal. Daarbij werden 3 onderzoeksvragen bestudeerd:

1) Hoe ervaren zogeheten kwetsbare ouderen zelf die kwetsbaarheid?
2) Hoe ervaren kwetsbare ouderen hun 'welbevinden'?
3) Welke factoren of randvoorwaarden zorgen ervoor dat kwetsbare ouderen een positief welbevinden hebben?

Doorheen die drie vragen onderzochten we welke rol het Zorg24 project daarin speelt. Om die onderzoeksvragen te beantwoorden, gebruikten we de interviews met 18 cliënten die hulp en ondersteuning kregen via en van Zorg24.

Betreft de eerste onderzoeksvraag rond kwetsbaarheid tonen de resultaten, in overeenkomst met eerder onderzoek (Grenier, 2006), dat ouderen hun kwetsbaarheid als heel breed ervaren. Ouderen blijken niet alleen fysiek kwetsbaar te zijn; ook getuigenissen rond psychische, omgevings-, cognitieve, financiële, administratieve en digitale kwetsbaarheid komen vaak voor. Dat maakt dat aangepaste zorg ook aandacht moet geven aan, en inspelen op die verschillende vormen van kwetsbaarheid en niet enkel op het fysieke. De cliënten van Zorg24 waarderen dan ook sterk dat er door de zorgverstrekkers de nodige ruimte gelaten wordt: voor die emotionele ondersteuning waarmee ze niet bij hun kinderen terecht kunnen, voor die sociale contacten, etc. Uit de

interviews komt regelmatig naar voren dat ouderen zichzelf niet per se kwetsbaar voelen, dat ze aanvaarden dat er een 'achteruitgang' is op een aantal vlakken, maar dat ze voelen dat anderen hen als kwetsbaar behandelen en hen daardoor ook kwetsbaarder maken. Dat kan zijn doordat anderen hen betuttelen en door een gebrek aan respect, maar ook de bredere samenleving lijkt hen te discrimineren en uit te sluiten.

Ondanks de negatieve gevolgen die kwetsbaarheid kan hebben, geven ouderen vaak aan dat zij een goede kwaliteit van leven, zingeving, zelfregie en gevoel van inclusie hebben, en kwaliteitsvol thuis kunnen blijven wonen (cf. onderzoeksvraag 2). Zelfregie was een belangrijk aspect. Het ging dan niet zozeer over volledige onafhankelijkheid of autonomie, maar over het eigenaarschap kunnen bewaren, en hoe de omgeving en zorgverstrekkers daarin kunnen ondersteunen. Tronto (1993) noemt dit ook wel 'relational autonomy' waarmee hij een waardevolle opening maakt in het discours rond autonomie dat eigenlijk impliciet stelt dat kwetsbare ouderen "(zorg)*afhankelijk*" en dus niet onafhankelijk/autonoom zijn (Tronto, 1993). De term relational autonomy legt sterker die nadruk op een ondersteunde autonomie, waarmee men dus verwijst naar zorg die als doel heeft om de autonomie van de oudere te verhogen. Verpleegkundigen en andere zorgberoepen die dicht bij de ouderen staan binnen het Zorg24 project zorgen ervoor dat zelfstandigheid behouden blijft waardoor gebruikers een waardig, kwaliteitsvol en zinvol leven kunnen behouden. Het zijn de kleine extra's die kwaliteit geven aan het leven van de cliënt. Om totaalzorg te garanderen in dergelijke zorgvernieuwende projecten wordt casemanagement toegepast, een collaboratief proces van assessment, planning, coördinatie, evaluatie en belangenbehartiging. Dit wordt idealiter uitgevoerd door een verpleegkundige (Durme et al., 2016). Binnen Zorg24 was dit ook het geval.

Betreft de derde onderzoeksvraag rond factoren of randvoorwaarden tonen de resultaten dat ervaringen dat persoonlijkheidskenmerken en coping strategieën van belang zijn. Andere zogeheten 'balancerende factoren' waren de omgeving (sociale omgeving, fysieke buurtomgeving, aanwezigheid van mantelzorgers), en macrokenmerken (financiële betaalbaarheid, administratie en maatschappelijke evoluties). Tot slot blijken ook bepaalde levensgebeurtenissen ervoor te kunnen zorgen dat ouderen terecht komen in een kwetsbare situatie, zoals het verliezen van de partner of een valpartij. Anderzijds tonen

de resultaten aan dat bepaalde levensgebeurtenissen een 'positieve' kanteling kunnen veroorzaken (bijvoorbeeld de geboorte van een kleinkind). Meer oog hebben voor dergelijke kantelmomenten of transities is een aanbeveling (Fredriksen-Goldsen et al., 2017).

Deze studie heeft een aantal sterktes. Dit is het eerste onderzoek dat verschillende positieve uitkomstmaten includeert in kwetsbaarheidsonderzoek. Door gebruik te maken van een gevalideerde meetschaal (CFAI) konden we kwetsbaarheid vergelijken met de subjectieve kwetsbaarheid die naar voor kwam uit de kwalitatieve interviews. Een andere sterkte was de beperking van interpretatieve bias door elke analyse tweemaal uit te voeren. Eveneens zijn er tekortkomingen: één is dat deze resultaten door hun kwalitatieve analyse niet kunnen veralgemeend worden naar de gehele populatie. Door 18 ouderen te bevragen naar hun ervaring binnen dit project werd wel een duidelijk beeld over de meerwaarde van Zorg24 gekregen. Daarnaast willen we meegeven dat de interviews werden afgenomen in de wintermaanden. De korte dagen en het uitzicht voor sommigen naar een eenzame eindejaar periode kleurden mogelijks de antwoorden.

Vanuit de resultaten kunnen we beargumenteren dat aandacht voor welbevinden het eigenlijk doel van zorg is of zou moeten zijn. Het gaat niet zozeer over het genezen van kwetsbaarheid, over prolongeren van het leven, of het zolang mogelijk thuis blijven wonen. Ageing in place moet volgens ouderen een ageing well in place zijn en blijven. De interviews tonen ook aan dat Zorg24 daar zijn steen(tje) aan bijdraagt. Daarnaast moeten we ons wel de vraag blijven stellen wat de grenzen zijn aan de thuiszorg. Zorg24 duwde die grenzen met zijn nachtzorg al verder, maar hoever kan en wil men gaan? Uit voorgaand onderzoek zijn er signalen voor de grenzen van de thuiszorg en is residentiële zorg nodig. We kunnen dan ook een stap verder gaan en niet meer over 'ageing *well* in place' spreken, maar over 'ageing *well* in the *right* place' (De Donder et al., 2017).

Dat laatste is geen evidentie. Als zou blijken dat thuis wonen niet meer mogelijk is, is de bereidheid om te verhuizen bij ouderen bijzonder klein (Smetcoren et al., 2014). Daarvoor kunnen verschillende verklaringen uit eerder onderzoek worden gegeven. Ten eerste heb je de emotionele binding met de woning. Mensen zijn vertrouwd met hun woning waar ook

allerlei herinneringen zich afspelen. Vervolgens wordt een eigen woning ook gezien als het appeltje tegen de dorst. Daarbij wil men vaak de woning nog bewaren 'voor de kinderen'. Een derde reden waarom niet meer verhuisd wordt op latere leeftijd is omdat men schrik heeft de regie kwijt te raken. Verhuizen op latere leeftijd is immers vaak geen spontane, zelfgemaakte keuze. Deze keuze wordt regelmatig aangewezen, aangepraat, of opgelegd door de omgeving (Smetcoren, 2016). Tenslotte zijn er ook weinig mogelijkheden om naar toe te verhuizen. Eigenlijk kan je stellen dat er maar 3 woonvormen voor ouderen met zorgnoden zijn: naast de eigen woonst kan een oudere naar een assistentiewoning of woonzorgcentrum verhuizen. Er is dus weinig keuze om de "right place" te vinden. Er zullen zeker ouderen zijn die door de intensiteit van de zorg enkel gebaat zijn bij een opname in een woonzorgcentrum (40), maar meer alternatieven zijn nodig. Die alternatieve woonvormen, met innovatieve en creatieve aandacht voor zorg en ondersteuning, blijken echter (bijzonder) moeilijk van de grond te komen (Luijkx, 2015). Aangepaste zorg in een aangepaste woonomgeving blijven nochtans primordiaal voor het welbevinden van kwetsbare ouderen.

6 Conclusie

Dit onderzoek toont aan dat er voor ouderen in een zorgsituatie aandacht moet zijn voor verschillende vormen van kwetsbaarheid naast fysieke kwetsbaarheid alleen. Ondanks hun eigen kwetsbaarheid gaven ouderen aan een goede kwaliteit van leven en zingeving te ervaren, alsook zelfregie te behouden, het gevoel hebben nog mee te tellen en kwaliteitsvol thuis te kunnen wonen. Balancerende factoren voor deze kwetsbaarheid liggen op het individuele, omgevings- en macroniveau. Projecten zoals Zorg24 zorgen door hun zorggarantie ervoor dat ouderen kwaliteitsvol thuis kunnen blijven wonen op een locatie die zij wensen.

English abstract:

Aim: to research how frail community-dwelling older adults experience their frailty and their well-being. Also, to explore which factors ensure positive well-being for frail older adults in a guaranteed 24h care at home project (Zorg24).

Method: Qualitative study using thematic analysis on the narratives of 18 older adults enrolled in the Zorg24-project.

Findings: The experience of frailty is more complex than experiencing physical problems. Professionals support them with multiple aspects and enlarge their well-being. This leads to experiencing quality of life, meaning in life, mastery and inclusion. With the help of the Zorg24 project, frail older adults are able to age well in place. Factors for balancing the experience of frailty were found.

Discussion: Community care can be accomplished due to projects as Zorg24. Bearing in mind our ageing society, such projects will be needed in the future.

Conclusion: With the help of guaranteed 24h home care older adults experience a good quality of life, meaning in life, mastery and feelings of inclusion.

Keywords in MeSH: Frail Elderly, Independent Living, Quality of Life, Qualitative Research

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Chapter 4

Meaning in Life for Socially Frail Older Adults

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1 Abstract

Being connected with others is fundamental for the experience of a meaningful life. Unfortunately, several older adults have poor networks and are at risk of not having social support. The present study focuses on the experience of meaning in life as well as the loss of meaning for socially frail older adults. Interviews with 56 socially frail older adults were analyzed using the conceptual framework of Derkx' seven dimensions of meaning in life within a qualitative hybrid approach employing inductive and deductive thematic analysis. Results indicate that socially frail older adults experience meaning in life in different dimensions: purpose, moral- and self-worth, competence, coherence, connectedness, and excitement. When aging, losses were experienced in the dimensions of purpose, coherence, and connectedness. The article argues that home-care organizations and prevention programs aimed at reducing frailty are encouraged to include evaluations of meaning in life, supplementary to the dominant focus on (physical) health factors. There is a need for meaningful activities in organizations that ameliorate social connectedness for community-dwelling older adults.

Keywords: social networks, meaning in life, frailty, needs

2 Introduction

Frailty is an important topic in health practice and both gerontological and geriatric research demonstrates that the risk for frailty increases with age (e.g., Fried et al., 2001; Dury et al., 2016). The concept of frailty itself has been defined and operationalized in multiple ways (Boers & Jentoft, 2015). The frailty phenotype (Fried et al., 2001) and the frailty index [as the accumulation of health deficits] (Rockwood & Mitnitski, 2007) are most frequently used in research and clinical practice. Nevertheless, these are often criticized because they emphasize biomedical aspects and functional decline. Since the end of the last century, academics have stressed the need for a more multidimensional view of frailty, as they fear that the individual as a whole is endangered when attention to frailty solely concerns physical deficits. Multidimensional frailty operationalizations include psychological, social (Gobbens, van Assen, Luijkx, Wijnen-Sponselee & Schols, 2010), cognitive (Steverink, Slaets, Schuurmans, & van Lis, 2001), and environmental aspects

(De Witte et al., 2013; Dury et al., 2016). Moreover, Gobbens et al. (2010) and De Witte et al. (2013) include life-course determinants in their frameworks and stress that domains cannot be seen in isolation; interaction between these domains and life course determinants can influence adverse frailty outcomes.

Mortality, hospitalization, and institutionalization are most often researched as adverse frailty outcomes (Vermeiren et al., 2016). Only a small number of researchers include decrease of well-being as a consequence of frailty (e.g., Andreasen, Lund, Aadahl, & Sorensen, 2015). Recent developments, however, suggest that subjective well-being is a potentially protective factor for health and reduces the risk of chronic physical illness (Steptoe, Deaton, & Stone, 2015). Steptoe et al. (2015) distinguish three types of subjective well-being: evaluative well-being (evaluation of life satisfaction), hedonic well-being (mood) and eudemonic well-being (judgement about meaning and one's purpose in life). These types are all present in later life despite the prevalence of chronic illnesses or comorbidity that occur with aging (Steptoe et al., 2015). Although the latter type – meaning in life – has gained more and more attention in the fields of psychology and medicine (Brandstaetter, Baumann, Borasio, & Fegg, 2012), its use in frailty studies is limited. Besides, this appears to be a promising avenue as studies have pointed to the advantages of meaning in life in later life (Battersby & Phillips, 2016). The experience of meaning in life has a protective factor as it empowers people and creates resilience against the misfortunes experienced by older adults (Ryff & Singer, 2008).

There is a tendency to agree that meaning in life is a multidimensional construct, but it is defined and measured in numerous ways (for a review, see Brandstaetter et al., 2012). For this research, the integrative, conceptual framework of Derkx is used (Derkx, 2013; Derkx, 2015). Derkx includes several of the traditional paradigms on meaning in life and incorporates seven needs for meaning in his conceptual framework.

Early research on meaning in life builds upon the concepts Viktor Frankl discussed in his book *Man's Search for Meaning* (Frankl, 1959). His work, for instance, led to the development of the purpose-in-life test (Crumbaugh, 1968) and Frankl's emphasis on the motivational dimension of meaning was included in the four needs for meaning proposed by Baumeister (1991). The concept of 'meaning needs' is described as a motivation to *find*

certain types of answers or explanations (Baumeister, 1991, p. 30). These four needs encompass (1) purpose, (2) value, (3) efficacy, and (4) self-worth; one will feel that life has sufficient meaning when these four needs are satisfied. Purpose can either be intrinsic or extrinsic, an inner fulfillment or reaching a goal. Baumeister (1991) shows that people wish to have purposeful activities––which do not have to be pleasant activities––and that these are related to the future. Value, as a need for meaning, can be described as the belief that one's actions and way of living are right, good, and just. The need for a sense of competence, control, or efficacy refers to the fact that people want to think they have a say in their own lives, that life does not merely happen to them, and that their own choices and decisions matter in the course of their life. The fourth need for meaning is self-worth. For this need, one needs to value oneself in a positive way that can either be seen as feeling better or superior to others or as a need for being valued or respected by others. Baumeister (1991) states that overlap between the four needs exists and that it is possible to combine needs or extend the list with more needs for meaning. It was Derkx (2013, 2015) who extended Baumeister's list with three other needs (Derkx, 2013; Derkx, 2015): (5) comprehensibility or coherence, (6) connectedness, and (7) excitement. Comprehensibility has found its basis in the work of Antonovsky's theory of salutogenesis (Antonovsky, 1987). Briefly, comprehensibility involves an interest in understanding and explaining the social world, in a desire for order rather than chaos. Connectedness can be expressed in several ways. It includes the need for caring and interaction with one or more friends and relatives or feeling united with something larger. As people look for curiosity in their lives, excitement was added as a seventh need for meaning (Derkx, 2013; Derkx, 2015).

An important source for meaning in life in older adults is relationships, even in the case when these relationships are shallow (O'Donnell et al., 2014; Stillman & Lambert, 2013). Older adults, for example, often depend on relationships in their social environment for support (Gray, 2009), attachment, reassurance of worth, opportunities for nurturance, and reliable alliances (Weiss, 1973). With aging, however, gaps may arise in support resources due to illness, death of loved-ones or other life events, making it hard for older adults to rely on someone for emotional and practical support (Rook, 2009). Several authors (e.g. Bunt, Steverink, Olthof, C., van der Schans, & Hobbelen, 2017, Duppen et al., 2017, De

Witte et al. 2013) use the concept of social frailty when referring to this lack of support. Social frailty differs from loneliness alone as it includes both resources to fulfill basic social needs as well as social loneliness. The social domain has been longtime neglected in frailty research (Markle-Reid & Browne, 2003). In the last decade, however, multidimensional frailty is more and more acknowledged in research and practice, and several instruments were validated to measure social frailty as a subdimension of frailty such as the Tilburg Frailty Indicator (Gobbens et al., 2010) or the Comprehensive Frailty Assessment Instrument (De Witte et al., 2013). Recent research on risk profiles of multidimensional frailty in community-dwelling older adults indicates that the risk for social frailty is higher than any other dimension of frailty and particularly affects older adults who have less income, are not married, and have moved in the last ten years (Dury et al., 2016).

Because of this importance of social connections for meaning in life, and because of the reduced social resources of older adults, this qualitative study sought to address how social frail older adults experience meaning in life. Guided by the seven needs for a meaningful life (purpose, value, efficacy, self-worth, comprehensibility, connectedness and excitement), this research study explores two questions with a focus on socially frail older adults:

1. How do socially frail older adults experience meaning in life?
2. Do socially frail older adults experience a loss or shortage of meaning in life?

3 Method

3.1 Research Approach and Data Collection

The data used in this qualitative study were collected from a larger mixed method study with frail older adults who participated in the Detection, Support and Care for older people – Prevention and Empowerment (D-SCOPE) project. This four-year project investigates strategies for proactive detection of (potentially) frail community-dwelling older adults, in order to guide them to the right support and/or care with a strong focus on empowerment. During the winter of 2015–2016, 121 older adults at risk of frailty were interviewed. In general, the larger study aimed to examine (a) how older adults perceive frailty, quality of

life (QoL), mastery and meaning in life, and (b) the balancing factors that influenced frailty and outcome variables, such as individual factors (e.g. coping, activities of daily living) and environmental factors (e.g. social networks). Results of the larger study can be found elsewhere (Dury et al., 2018; van der Vorst et al., 2017). In the present study that focusses on meaning in life, an analysis was carried out on the data of participants who scored high or mild frail on the social domain on the self-assessment Comprehensive Frailty Assessment Instrument (CFAI) (De Witte et al., 2013).

3.2 Participant Recruitment and Participants' Characteristics

Participants were recruited in the Flemish speaking area of Belgium and the city of Brussels, Belgium, using snowball sampling and the help of five home-care organizations. Participants were excluded from the study in cases of hospitalization, when the older participant or the informal caregiver indicated that the older adult was unable to participate, or when the interviewer noted that the older participant was unable to provide adequate answers. For the present study, only the qualitative data from (mild) socially frail participants were derived from semi-structured interviews. The social domain of frailty in the CFAI combined a measurement for social loneliness through propositions from the shortened 'Loneliness' scale (de Jong Gierveld & van Tilburg, 2008) and a measurement for social support. In the latter measurement, insight is gained into the potential support network by asking if the respondent could rely on help, if necessary, from one to ten different persons in the immediate vicinity (De Witte et al., 2013).

Table 4.1 presents an overview of the participants' characteristics. In total, data from 56 out of 121 participants were included for this study. Only these participants were selected who scored (mildly) frail on the social domain. Apart from being socially frail, they were often also frail for other frailty domains (physical, cognitive, psychological, or environmental). Of the participants, 34 were female, 22 were male, and the mean age was 79.3 years (range 64–94). Older adults with a migration background were deliberately included in the D-SCOPE project. For the present study, 7 participants had a migration background, 49 were Dutch speaking, and 5 French speaking. An interpreter was present at the time of the interview for one Italian-speaking and one Turkish-speaking participant.

3.3 Interview Scheme and Data Analysis

All interviews were digitally recorded with the participant's permission and transcribed verbatim. Each interview opened with the question "How do you experience frailty and what does frailty mean to you?" Depending on the participant's answer, the interviewer went more into detail and further asked if frailty had an effect on their meaning in life, and what gave meaning in their life. Subsequently, the other questions followed. For more information on the entire study design, see Dury et al., 2018. A panel of experts (see acknowledgements) approved all the questions, helping to ensure the content validity of the interviews (Boeije, 2010).

A hybrid approach of inductive and deductive thematic analysis was used, as discussed by Fereday and Muir-Cochrane (2006). For the deductive analysis, the conceptual framework of seven needs for meaning (Derkx, 2013; Derkx, 2015) were used a priori in the development of the code manual, these were the main labels. In order to detect sublabels, inductive analysis was used. New themes that emerged from the interviews in the analysis were appointed to a sublabel.

Three researchers were involved in the coding process. First, one researcher from the D-SCOPE project and one researcher experienced in meaning in life research - but not involved in the project - separately coded six identical interviews for the development of a code manual. After this step, two researchers coded the interviews. The first researcher participated in the development of the code manual and coded the Dutch and interpreter-assisted interviews. The second researcher, also involved in the D-SCOPE project, coded the French interviews. The stages of data coding delineated by Crabtree and Miller (1999) were used as a guideline in this procedure. In this iterative process, findings were first discussed with two other D-SCOPE researchers. To increase credibility and to foster reflexivity, findings from the deductive analysis and new insights from the inductive analysis were again discussed with the researcher experienced in meaning in life research who was not involved in the D-SCOPE project. All suggestive interpretations and assumptions were deleted. In the final step, all researchers involved in this study discussed and weighed the interpretations ('investigator triangulation,' Patton, 2015: 316)

Table 4.1: Characteristics of participants.

Code	Age	Sex	Marital status	Soc	Cog	Psy	Phy	Env	Total
R1	80	Female	widowed	++	++	++	++	++	++
R2	74	Female	never married	++	++	++	++	++	++
R3[a,b]	81	Female	widowed	++	++	++	++	+	++
R4	75	Female	divorced	++	++	++	+	++	++
R5	89	Female	never married	++	+	++	++	++	++
R6	79	Male	divorced	++	++	++	+	++	++
R7	69	Female	divorced	+	++	++	++	++	++
R8[a,b]	66	Female	widowed	++	++	++	++	-	++
R9	92	Female	widowed	++	++	++	+	+	++
R10	85	Female	widowed	+	++	++	++	+	++
R11	72	Male	widowed	+	++	++	++	+	++
R12	80	Female	widowed	+	++	++	++	+	++
R13	76	Male	widowed	+	++	+	++	++	++
R14	80	Female	widowed	+	++	+	++	++	++
R15	75	Male	widowed	++	++	++	-	+	++
R16	78	Female	married	++	++	+	+	+	++
R17	78	Male	widowed	++	++	+	+	+	++
R18	91	Female	widowed	++	++	+	+	+	++
R19	81	Female	widowed	+	++	++	+	+	++
R20[a]	81	Female	widowed	+	++	++	+	+	++
R21	82	Male	divorced	+	++	+	++	+	++
R22	80	Female	widowed	+	++	+	++	+	++
R23	72	Female	widowed	++	+	+	+	++	++
R24	93	Female	widowed	+	++	++	+	-	++
R25	94	Female	widowed	+	++	-	++	+	++
R26	86	Female	widowed	+	++	++	+	-	++
R27	85	Female	married	+	++	+	+	+	++
R28	81	Male	widowed	+	++	+	+	+	++

[a] = migration background, [b] = interpreter present at the interview, [c] marital status as official registered, it was nonetheless possible for never married, divorced and widowed persons to have a partner, which is not registered here. Soc = social frailty, Cog = cognitive frailty, Psy = Psychological frailty, Phy = physical frailty, Env = environmental frailty Total = Total frail, ++ = high frail, + = mild frail, - = no – low frail, *m* = missing

Table 4.1: Characteristics of participants *(continued)*.

Code	Age	Sex	Marital status [c]	Soc	Cog	Psy	Phy	Env	Total
R29	84	Male	widowed	+	++	-	+	+	++
R30	70	Male	widowed	+	++	++	-	++	+
R31	73	Female	never married	+	++	++	-	++	+
R32[a]	75	Female	widowed	+	++	++	-	+	+
R33	83	Female	widowed	++	+	-	-	+	+
R34	81	Male	married	++	+	+	+	+	+
R35[a]	68	Female	widowed	+	++	+	+	+	+
R36[a]	70	Male	widowed	+	++	+	-	+	+
R37	86	Male	married	+	++	-	+	+	+
R38	72	Male	living together	+	++	-	+	-	+
R39	80	Female	married	+	+	+	+	+	+
R40	74	Female	never married	+	+	-	-	+	+
R41	67	Female	widowed	+	-	+	-	+	+
R42	89	Male	widowed	+	-	+	-	+	+
R43	76	Female	never married	+	+	-	+	+	+
R44	88	Female	widowed	+	++	+	-	-	-
R45	69	Male	widowed	++	+	-	-		-
R46	77	Male	married	+	++	-	-	-	-
R47	78	Male	widowed	+	++	-	-	-	-
R48	74	Male	married	+	++	-	-	+	-
R49	65	Male	divorced	+	+	-	-	+	-
R50	90	Male	widowed	+	+	-	-	+	-
R51	64	Female	divorced	+	+	-	-	+	-
R52	90	Female	never married	+	-	-	-	-	-
R53[a]	89	Female	divorced	+	++	*m*	++	+	*m*
R54	85	Male	widowed	++	*m*	+	++	*m*	*m*
R55	90	Male	widowed	+	*m*	++	-	+	*m*
R56	77	Female	divorced	+	*m*	+	+	+	*m*

[a] = migration background, [b] = interpreter present at the interview, [c] marital status as official registered, it was nonetheless possible for never married, divorced and widowed persons to have a partner, which is not registered here. Soc = social frailty, Cog = cognitive frailty, Psy = Psychological frailty, Phy = physical frailty, Env = environmental frailty Total = Total frail, ++ = high frail, + = mild frail, - = no – low frail, *m* = missing

3.4 Quality Procedures and Ethical Approval

To extend the *reliability* of the interviews (Boeije, 2010), nine interviewers were trained before the interviews. For content validity in the interviews (Boeije, 2010), the topic list was developed together with the entire D-SCOPE research group, which consisted of 21 researchers in several disciplines (e.g., old age medicine, psychology, educational sciences, etc.), although all researchers were specialized in gerontology and/or frailty. A commonly used strategy to extend credibility in qualitative studies is to give study participants the opportunity to discuss the research findings; however, it was impossible to discuss the study's findings with the participants because they had been guaranteed anonymity and therefore a member-check could not be held. The D-SCOPE study was approved by the Ethical Commission Human Sciences of the Vrije Universiteit Brussel (ECHW_031). All participants signed an informed consent agreement.

4 Results

4.1 Meaning In Life Of Socially Frail Older Adults

The experience of meaning in life of social frail older adults is presented with respect to each category of need for meaning as constructed by Derkx. In general, we see that older adults' experience of meaning in life is mostly derived from three or more different needs. Older adults do not delineate their meaning in life using one need, but actually talk about meaning in life according to different needs.

Purpose. The need for purpose is seen as connecting life and activities in the present with something of positive value in the future. For the socially frail older adults in this study, with the exception of one person (also the youngest and least frail whose purpose was to go abroad), no respondents had specific plans or goals with a positive value in the future. Nonetheless, it is possible to differentiate two main findings concerning this dimension. First, several respondents just wanted to continue their daily activities (e.g., going to the service center) as usual, take life as it comes, have some expectations but not too many.

> *For me it is the daily life: getting up, drinking coffee, doing the housework driving to my mother, reading… especially reading. The daily life, no excesses. (Divorced woman, 65 years)*

Second, when a sense of purpose was present, it was described as inner fulfillment without the need to reach a goal or to develop a personal talent. Many respondents found fulfillment in hobbies, going out, and in activities at home. For others, these inner fulfilments overlapped with the need for connectedness with children or grandchildren.

Value/Moral Worth. Respondents often experienced their way of life as positive and morally worthy. Being able to solve problems in the family, not giving up when problems occur and living soberly without losing joy in life were examples that found their origins in education, religion, or memories of World War II. Some respondents expressed philanthropic thoughts and hope for the future, and referred to the Charlie Hebdo attacks in Paris 2015 that took place in the months before the interviews. Altruistic deeds also demonstrated respondents' moral worth:

> *A lot of things go lost in a day and sometimes it [happiness] can be found in small things. Those things have an enormous impact on your day. In the morning, when you meet someone who is kind to you, you will feel that for the whole day. (Married man, 86 years)*

Efficacy/Competence. Being frail does not mean one automatically loses competence. Despite being frail, respondents frequently confirmed that they were able to maintain a level of control and autonomy in their lives and this level of control varied between individuals. Also, being able to make one's own choices and not being dependent for small things in the household was important, along with control over finances and having mastery over formal caregiving.

One way to keep control was to adjust the environment and make it fit with what one wanted or to adapt to the environment. Adjusting to the environment did not occur clearly in the interviews. One respondent adjusted her caring environment by moving all necessary furniture and products to the ground floor in order to continue living in her own house. In the interviews "adapting to the environment" was mostly identified as adapting to situations. One respondent's adaptive coping strategy was to change her way of managing household activities:

A couple of years ago, I fell. The doctor said: "The only thing you won't be able to do from now on is doing the dishes." Then I look at him and said "Man, we'll see about that when I get back home!" "No," he said, "You are going to leave those dishes, it will hurt your back, holding your hands in front of you..."
Now, I have a lot of dishes to do, and sometimes I do them in three times. And it hurts, and it burns. Yes, then I take a break, I rest and afterwards I start again. (Divorced woman, 75 years)

Self-Worth. The need for self-worth is mostly seen as valuing oneself positively and having the opportunity to be recognized and respected by others. Two distinctions of self-worth can be identified in the interviews. The first type is 'self-worth in comparison with others'. Here, older adults often compared themselves with their institutionalized or dependent peers, or they mentioned that they themselves only needed a minimum of professional help.

I was digging in my garden the other day. Many people of my age are – if they are still alive – in a wheelchair. And I still ride my bike every day. (Widower, 89 years)

The second type of self-worth that emerged in the interviews is pride in physical appearance or pride in one's own realizations. Examples are maintaining visits to the hairdresser, buying new clothes, or leaving a successful business to the children. A peculiar type of pride is the embarrassment of asking for help and the fear of being seen as frail, or dependent, or unsuccessful. One lady without a support network experienced loneliness because she was not able to go to organized activities:

Oh yes, I miss people around me. But I can't go (to activities). They ask me though: "Aren't you joining us? It's an evening organized by the community or the Catholic Union." It's always elegant and in the community hall. But what if I get too tired? I will have to annoy someone by asking: "Can you drop me off at

(address)?" This person's pleasure will be gone then. You always have to bother someone. And I don't like that, I used to drive myself, I lost my independence. (Widow, 80 years)

Coherence. Coherent stories make life comprehensible and manageable, and provide a firm identity and continuity. Here, having a clear structure such as living their lives in familiar ways implied continuity.

I: What gives meaning to your life?
R: My husband, and comfortable living. Yes, I like it here. I like living here, and I hope it can last. (Woman, 80 years)

Many of the respondents could explain the events that happened to them, knew their own limits, or understood the world they live in. They understood that they had to retire, that loved ones died, that children moved away to live their own life, and that the world they lived in had become smaller. They understood that they were frail and the limits this frailty imposed, or that the condition they had (e.g., Parkinson's disease) would worsen in the future. Some of them tried to manage their life which made them feel somewhat less frail:

If you understand the reality of life, you are less frail. If you don't, it's dead. (Widower, 78 years)

Another way of understanding life events is by negotiating the circumstances. These respondents found a way, for example, to continue their life in a wheelchair. Another example came from a (never married) woman who was fine with every change as long as she could continue her handicrafts.

Connectedness. The need for connectedness became apparent in a number of different ways. First, a range of respondents found meaning in being connected with a partner, friends, family, in-laws, or even professional caregivers despite being socially frail. When they spoke about long lasting family conflicts or disagreements, some pointed out that there was still a meaningful connection with these relatives.

Second, several older adults responded to the need for connectedness by focusing on what others need of them. In some ways, they felt obligated to keep up with their life for their children's sake or found that others motivated them to continue their life.

> *My anti-depressants, I should never stop that. I asked once and the neurologist said no. Because I will fall very deep the moment something goes wrong and I won't tide over again. I'm good with it for the moment but sometimes I say … after all, I won't harm myself, I do love my family too much for that. That's what supports me, being able to see my grandchildren grow up. After all, that's why you go on. (Married woman, 78 years)*

Third, the need for connectedness for some respondents was found in their religion or spirituality. Included in this spirituality, a few respondents found meaning by retaining a deep connection with their deceased partner or relative:

> *There are days when nothing matters anymore. But I am here because she (deceased wife) helps me to be here. (Widower, 75 years)*

Excitement. Three main themes were noted in this domain. The first was in transcending daily life, such as by being away from daily activities, celebrating an anniversary, or a newborn in the family, or going on holiday:

> *Translator: At the moment, she is counting the days until May because she will go back to Turkey. There she has more joy in life because her children and grandchildren live there. (Divorced woman, 79 years)*

A second theme was the enjoyment of beauty in life. This beauty was found in art and culture, fauna and flora, and the beauty in everyday life, such as watching little children walking with parents in the streets. A third theme was in transcending 'the known', such

as being surprised when new and exciting things happened that gave meaning again. One respondent expressed her desire for meaningful activities when the city services invited her to join a lecture:

> *The community civil servant called for a lecture about public transport and older adults. That's what I want, something with content! Instead of singers and meals (sighs). (Widow, 80 years)*

4.2 Loss of Meaning?

A loss or shortage of meaning in life was found in three of the seven dimensions: purpose, coherence, and connectedness. Respondents described this loss as a result of getting older or having a smaller network. Not all respondents mentioned a loss of meaning. Others indicated there was a single loss. A group of respondents, who experienced difficult situations and stressful events throughout their lives, elaborated on a series of losses. Nonetheless, and even in the most grievous stories, respondents responded to the loss of meaning by "satisfying" at least one other need for meaning and so compensating the experienced loss.

Lack of Purpose. When respondents stated that there was a lack of purpose in life, they referred to a time when they had more purpose and that purpose had faded away as a result of children that grew older, retirement, or disease. One woman with a work history in Human Resources explained it as follows:

> *People came to me with their problems. I had to hire them and I had to fire them. With all their problems, they came to me. For years I was like a service center. And that was erased for 95%. Also, children and grandchildren don't need me anymore. (Widow, 80 years)*

Lack of coherence. A minority of the respondents experienced a lack of coherence. Some felt vulnerable and were afraid of the future after a loved one's death. The ending of such relationships gave a smattering of knowledge about the future. Although they understood

their frail situation and the events that had taken place, they did not find it easy to continue life alone. Lack of coherence was also found in stories where respondents said they felt more vulnerable than they used to be:

> *With age, you become more sensitive. You used to ignore things but now you feel that they hurt you, honestly. I am more emotional than I used to be. On the one hand, because I have been through much I could say "I don't care!" and "that's life!" On the other hand, not anymore, now it hits me harder. (Widow, 72 years)*

Shortage of connectedness. The shortage of social connectedness was described in numerous ways: First, the death of a spouse, friend(s), or children could lead to a loss of meaningful relationships and the difficulty of finding new friends. Second, networks change over time: Conflicts with children or in-laws, divorce, or separation from a partner could lead to smaller social networks. One older woman, who lost contact with her grandchildren after a conflict with her daughter in law, tried to rectify this loss and aspired to reconnect with one of her grandchildren through using social media. Neighbor networks can change as well: Familiar contact is lost when peers move and younger people move into the neighborhood. Third, quite a few respondents were selective in their relations and two types of selectivity can be distinguished. In the first type, respondents were investing in a selective group of relations where people are bonded by family ties or bonded by similar interests. The second type had no desire for connectedness owing to conflicts or trust issues with neighbors or relatives. However, they expressed a wish for contact with other people. An older childless widow with family disputes had stayed inside her house since her husband died until her general practitioner forced her to go to a service center:

> *R: The service center, I started to go there this year, I had to.*
> *I: How come?*
> *R: My general practitioner told me, because I cried here all day long. I didn't eat anymore. My husband died and I ate only sandwiches with syrup for two years. My food didn't [have] taste*

alone, it didn't taste. And now I eat there every Thursday but alone it doesn't [have] taste.
I: So, your general practitioner told you to go there?
R: Yes, he told me, but it's only once a week, that's not enough. Three times a week would be better, because people really look forward to that day. (Widow, 80 years)

Fourth, being physically frail sometimes led to being socially frail (e.g., not being able to reach the neighbors' fence) and older adults often wished for more contact with others. Some care-dependent older adults were literally waiting throughout the day for the next professional to arrive, as these were the only people with whom they have contact. Last, being an informal caregiver for a physically frail partner also led to being socially frail.

5 Discussion

Against a dominant background of negative health or adverse outcomes in frailty research, the present study focused on the experience of meaning in life for socially frail community-dwelling older adults. The findings of this study indicate that socially frail older adults do experience meaning in life. Using a hybrid approach of inductive and deductive thematic analysis, this study illustrates that seven needs for meaning can be distinguished as described in the conceptual model of Derkx (2013, 2015): purpose, moral worth, competence, self-worth, coherence, connectedness, and excitement. The findings illustrate that respondents experienced a loss of meaning for purpose, coherence, and connectedness. Results received from the inductive thematic analysis in this study suggest a refinement of this model: It is not necessary to satisfy all seven needs to experience one's life as meaningful. Specifically, one could have a low sense of purposefulness for the future and, all the same, find meaning in the fact that one is able to continue his or her life despite being frail. Generally, there could be a strong emphasis on one need for meaning and less emphasis on other needs without experiencing a shortage of meaning. Respondents who experienced a shortage in one or more types of meaning compensated for the loss with another type.

The findings suggest that the social environment is an important factor in satisfying needs for meaning as well as the cause for loss of meaning. Earlier research confirms that meaning in life is found in human relationships and is associated with the lived circumstances of older adults (Hupkens, Machielse, Goumans, & Derkx, 2016). In this study, the remaining relationships were an important source of meaning. Apart from family ties, neighbors, professional caregivers, and local officials were alleged to be relationships that provided meaning. Further meaning was found in being a spectator of daily life and participating in organized activities. All these sources are dimensions of the social environment (Duppen et al., 2017) and appear to be crucial to the experience of a meaningful life. Losses in need for meaning in relation to the social environment became apparent in the purpose and connectedness dimensions. Older adults' networks change over time and former social roles as active professionals or (grand)parents may disappear. These results fit with the theoretical framework of Kahn and Antonucci's convoy model of social relations. These social convoys are seen as dynamic and are shaped both by personal and situational factors during the life course (Antonucci & Akiyama, 1987; Kahn & Antonucci, 1980). Two reasons for maintaining a small network remain: First, frail older adults found it hard to establish new relationships because of physical frailty or disabilities. Similar results were found in a recent study on lost relationships in old age (Tiilikainen & Seppanen, 2017). Second, several respondents preferred to have meaningful relationships with only a selection of other people who are closely related or share the same interests. This selectivity in relationships was previously theorized as the socio-emotional selectivity theory by Carstensen: Older adults who feel that less time is left in their life prefer to invest their time in positive emotional relationships rather than expanding their social network (socio-emotional selectivity theory (Carstensen, 1991)).

Several limitations should be noted. First, the respondents for this study were not a homogenous group of socially frail older adults. They were either mildly or highly frail in the social frailty domain and almost all were frail on one or more other frailty domains. Second, different researchers conducted the interviews and there may have been inconsistencies between interviews. Third, during the interviews, a relative was occasionally present or nearby, which is a possible source of bias as socially desirable responses might have been given. Fourth, given the qualitative design of the study, findings cannot be generalized to

all socially frail older adults. Finally, in general, we found that the respondents of this study sometimes lacked the language to explain what gave meaning to their life. The conceptual model of Derkx provided a valuable a posteriori explanation in this study. Further qualitative research with a specific focus on these seven dimensions could be beneficial. With respect to other valuable frameworks such as Antonovski's 'salutogenesis' (Antonovsky, 1987) or Lawtons's 'valuation of life ' (Lawton et al., 2001) that are also frequently used in gerontological research, this study opted for the concept of Derkx given it's multidimensional character that includes both the aspect of comprehensibility in salutogenesis or worth that is central in valuaton of life measure. To our knowledge, this is the first study to include meaning in life in frailty research. The qualitative design of the study however does not provide information as to whether less meaning in life is a result of higher levels of social frailty or vice versa. Quantitative research considering meaning in life among frail older adults and other aspects of well-being may resolve this issue.

Several implications for practitioners in the field of home-care or community service can be derived from the study. Home-care professionals often focus their work toward practical needs and healthcare issues, and their work in preventing frailty from worsening is undeniable. There should, however, be a greater awareness of methods to support the improvement of meaning in life rather than simply a concern with illness and disability (Steptoe et al., 2015). Our results indicate that professionals can even be a source for meaning in life themselves. Because leisure activities provide meaning, a second implication is relevant to community organizations, clubs, or community officials, who are responsible for ameliorating social or civic participation. Participation in social or leisure activities enables aging in place (Tomioka, Kurumatani, & Hosoi, 2016) and has frequently been associated with health benefits (e.g., Kim, Kim, MaloneBeach, & Han, 2016; Tomioka et al. 2016) and better quality of life (Levasseur, Desrosiers, & Tribble, 2008; Zhang & Zhang, 2015). A recent study in a group of frail older adults in The Netherlands found that the group had no desire for social or civic participation as it was irrelevant to their well-being (Van Dijk, Cramm, Van Exel, & Nieboer, 2015). In contrast, most respondents in this study appreciated these organized activities although one respondent explicitly wanted to have meaningful activities that exceeded the usual coffee gatherings in her local service center. Prevention programs aimed at reducing frailty should include evaluation of meaning in life, supplementary to the usual focus on health factors.

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Chapter 5

Focusing on Positive Frailty Outcomes: Development of a Short Well-being Instrument for Older Adults (SWIO)

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1 Abstract

Background: Most studies in frailty research focus on adverse frailty outcomes. Therefore, this study aimed to develop a short instrument that identifies a positive outcome, namely the level of well-being in frail community-dwelling older adults.

Methods: 871 community-dwelling older adults (49.4% women; mean age 75.72 years; SD = 8.05) with a frailty risk profile participated in the first wave of the D-SCOPE study. Exploratory Structural Equation Modelling (ESEM) and multidimensional item response theory analysis on 17 items in 4 domains measuring well-being was performed on a calibration sample (n= 435) to develop the SWIO. The new SWIO subsequently was corroborated by confirmatory factor analysis and convergent/divergent relations with relevant external measures in a validation sample (n = 436).

Results: The ESEM 3-factor solution, with subdimensions sense of mastery, meaning in life and life satisfaction, displayed good fit to the data (RMSEA=0.070). For each dimension, by way of IRT analysis the 3 best discriminating items were retained for the SWIO. Internal consistency of these short dimensions was good (sense of mastery α=.864, meaning of life α=.715 and life satisfaction α=.782) in the validation sample and the CFA 3-factor model also showed good fit to the data (RMSEA=0.064). Small to large zero-order correlations with the external measures were in the expected directions.

Conclusions: this study developed a short instrument to identify well-being or a lack thereof in a group of vulnerable or frail community-dwelling older adults that can be applied in primary care and prevention programs.

Keywords: frailty – Item Response Theory – well-being – health outcomes – short form

2 Introduction

Frailty is a concept that is frequently used in aging research and care for older adults. While the majority of research mainly focusses on physical frailty, attention for the more holistic multidimensional frailty is increasing (e.g. Gobbens et al., 2010). Within this view, beside the physical domain, also other domains such as social, cognitive, psychological and environmental frailty are included (De Roeck et al., 2018). Moreover, the vast majority of research on outcomes for frail older persons focuses on medical, adverse health outcomes

such as mortality, functional decline, hospitalization, institutionalization and more (Vermeiren et al., 2016), often in order to investigate the (cost-) effectiveness of interventions (e.g. Metzelthin et al., 2015). Research on more positive outcomes such as quality of life is scarce (Kojima et al., 2016).

However, outcomes of being frail do not have to be solely situated on adversities or negativities. The inclusion of more positive frailty outcomes such as quality of life and/or psychological well-being (e.g. Clegg et al., 2014; Dury et al., 2017; Landi et al., 2017; van der Vorst et al., 2017; Walters et al., 2017), meaning in life and sense of mastery (Dury et al., 2018; van der Vorst et al., 2017) have proven to be very interesting too, but until now are, to our knowledge, only rarely studied. The few pioneering studies mentioned above have demonstrated that also frail older adults still can experience a sense of well-being. Therefore, the current study aims to further describe the importance of positive outcomes in frailty research and presents the development and validation of a brief instrument to measure positive outcomes by means of aspects of well-being in frail older adults. This instrument could be used both in research as well as in primary care and prevention programs to identify persons/groups at risk for lower levels of well-being.

When looking at different studies recognizing these positive outcomes, however, different dimensions or concepts to operationalize "positive outcomes" are used, like for example well-being which is an umbrella-concept. In this study we have chosen to cluster 4 domains of well-being which seems to be relevant in later life: meaning in life, life satisfaction, sense of mastery and community inclusion. First, eudemonic well-being or meaning in life has received more and more attention in the fields of psychology and medicine (e.g. Brandstaetter et al., 2012; Van der Heyden et al., 2015) and studies have demonstrated its particular relevance in old age (Battersby and Phillips, 2016). The second domain, life satisfaction, which is the more "evaluative" part of well-being has been added given the positive effect higher life satisfaction has on survival, even when people are ill (Chida and Steptoe, 2008). Sense of mastery is included as a third domain for well-being as having a higher sense of control on your own life has multiple positive effects in later life. Moreover, it can counteract the negative effects of frailty on functional decline (Lee et al., 2016). A qualitative study on positive frailty outcomes (Dury et al., 2018; van der Vorst et al., 2017)

revealed one additional domain of well-being expressed by frail older adults themselves, namely being able to participate or feeling included in the community. In order to be able to intervene and to improve sense of well-being in vulnerable groups, it is highly important to identify well-being or a lack thereof in early stages.

To measure each of these four domains separately, several instruments are available: for meaning in life [e.g. the valuation of life scale (Lawton et al., 2001) or the meaning in life questionnaire (Steger et al., 2006)], for life satisfaction [e.g. Satisfaction with Life Scale (Diener et al., 1985)] and for sense of mastery [e.g. sense of mastery scale (Pearlin et al., 2007)]. Combining all these relevant questionnaires of well-being would lead to a very long questionnaire. Questionnaire designs however in gerontological research should take into account the potential needs of the older target group in terms of accessibility, usability, and length (i.e. brevity) of the questionnaire (Converse & Presser, 1986; Fowler, 2002). Moreover, given the target group of frail older adults and the risk of fatigue when intensive questionnaires are used, respondent burden is a considerable issue (Rolstad et al., 2011). This study therefore aims to design a brief and user-friendly instrument, capturing all important domains of well-being and using already existing and validated scales. In search for an instrument that is both short and ensures that the used items of the subscales discriminate sufficiently, we will combine factor analytic and item response theory (IRT) approaches in order to develop a short scale measuring important aspects of well-being. Given the positive outcomes of well-being, it is especially important to have an instrument that can measure changeability in well-being in an efficient way. Such an instrument will also make it possible to evaluate the effectiveness of interventions by measuring changes in levels of well-being over the time.

3 Method

3.1 Sample

Data was gathered from 871 older adults (49.4% women) who completed the survey in the first wave of the D-SCOPE study in 2017. In three municipalities, participants were selected from the census records with a stratified sample based on risk profiles for frailty (Dury et al., 2016). More information on the study design and participants eligibility criteria can be

found in Lambotte et al. (2018). All participants were 60 years or older. The mean age was 75.72 (SD = 8.05). 38.5% was married or lived together with a partner. 6.6% was never married,19.2% was divorced and 35.5% was widowed. The latter two are higher than population averages as these marital statuses were purposefully sampled as risk profiles for frailty. 37,7% had a lower level of education (until age 14).

3.2 Measurement

Measures of well-being

Sense of Mastery (SOM) – 4 items that measure current mastery were derived from the sense of mastery scale (Pearlin et al., 2007). Based on qualitative interviews prior to this study (Dury et al., 2018), one self-constructed item to assess mastery in relation with others was added: "I can determine how I want things in my life".

Meaning in life (MIL) –The Dutch version of the 'presence' subscale of the Meaning in Life Questionnaire (5 items) (Steger et al., 2006) was used for the evaluation of meaning in life. Additionally, based on the same qualitative interviews prior to this study, one self-constructed item was added to the questionnaire to inquire their desire in future events by asking "I am looking forward to events in the future".

Life satisfaction (LS) – The Dutch version of the complete Satisfaction with Life Scale (5 items) was used in the questionnaire (Diener et al., 1985).

Community Inclusion (CI) – One item from the Community Integration Measure (CIM) was used to ask the participants to what extent they feel like part of the community (McColl et al., 2001).

For all measures, responses were given on a 5-point Likert scale ranging from 1 = totally disagree to 5 = totally agree. If no Dutch version was available for an instrument, a team translation approach called the Translation, Review, Adjudication, Pre-Testing and Documentation (TRAPD) was undertaken to translate the English questions into Dutch. The survey was screened by the organization "Wablieft", that checks the accessibility and clarity of language considering the frail target group.

External validation measures

Comprehensive Frailty Assessment Instrument plus (CFAI-plus) – multidimensional frailty was assessed according to the CFAI-plus (De Roeck et al., 2018; De Witte et al., 2013). This self-assessment instrument includes five domains of frailty. The physical domain is captured by assessing the respondent's general physical health (four items, e.g., walking up a hill or stairs). The psychological domain includes measurement of mood disorders and emotional loneliness (eight items, e.g., losing self-confidence). The social domain was evaluated based on social loneliness (three items, e.g., feeling close to other people) and potential social support network (ten items, e.g., partner, children, and neighbors). Environmental frailty was assessed based on factors related to the suitability of the physical housing environment (five items, e.g., insufficient comfort in the house). Finally, subjective cognitive frailty was assessed based on factors related to cognitive functioning (four items, e.g. memory problems). Scores for each domain, which theoretically range from 0 to 100, were calculated by adding the scores for the specific items (De Roeck et al., 2018).

Numeric Rating Scales – Five 1-item questions on a numeric rating scale (NRS) from 0 to 10 for quality of life (QOL), MIL, CI, SOM and subjective frailty were developed as part of the D-SCOPE project, e.g., "On a scale from 0 to 10, to what extent you feel part of the society?" The scores ranged from 0 (bad) to 10 (excellent) on an NRS. These 1-item questions were related to earlier D-SCOPE research (Dury et al., 2018; van der Vorst et al., 2017) and were used to gain insight into the older adult's feelings of frailty and overall experience regarding QOL, MIL, CI and SOM. Subjective frailty NRS was reversed to align with the frailty dimensions of the CFAI. See supplementary material appendix 4 for the NRS.

3.3 Analyses

The sample was randomly divided in a calibration (n = 435) and a validation sample (n = 436). The *calibration* sample was used to develop a **s**hort **w**ell-being **i**nstrument for **o**lder adults (SWIO). First the underlying structure of well-being was evaluated for all potential items by performing exploratory structural equation modeling analyses (ESEM; see Marsh et al., 2014) using Mplus. The fit of the successive factor solutions was evaluated using the following goodness-of-fit criteria: The Tucker-Lewis Index (TLI), the comparative fit index

(CFI), the standardized root mean square residual (SRMR), and the root mean square error of approximation (RMSEA). For an acceptable fitting model rules of thumb are TLI ≥ .90, CFI ≥ .90, RMSEA ≤ .08 (RMSEA interval ≤ .10), and SRMR ≤ .08 (Chen et al., 2008; Hu and Bentler, 1999). To decide on the number of factors these goodness-of-fit criteria are used in combination with interpretability of the factors. Items were considered to substantially load on a factor if the factor loading was significant and at least .32 (Tabachnick and Fidell, 2013). Next, the SWIO was developed. A priori decision was made to shorten the scales to measure the underlying factors to 3 items, to optimize brevity of the instrument while still allowing the use of the dimensions in structural analyses. For the SWIO, only items were selected that have substantial factor loadings and to further optimally shorten the scale IRT modeling was additionally used to include the most discriminating parameters. In IRT the *a* parameter is the discrimination parameter and indicates the extent to which the item is related to the construct, the higher the parameter, the more discriminating the item is. IRT analyses were conducted with IRTpro (Cai et al., 2011). Since all items have 5 response categories with increasing valence, a graded response model was applied (Samejima, 1997).

The *validation* sample was used to cross-validate the instrument in an independent sample. First, using Mplus, confirmatory factor analyses was applied to statistically test whether the factor structure deduced in the calibration sample, based on the reduced number of items, showed acceptable fit in the (independent) validation sample by specifying patterns of relations a priori. Next, zero-order correlations of the subscales of the SWIO were calculated with all external validity measures and interpreted according to Cohen's *r* effect sizes (Cohen, 1988; .10 small, .30 medium and .50 large).

4 Results

4.1 Factor structure of all potential well-being items

ESEM (geomin rotation) was performed in the calibration sample. Factors were interpretable up to three factors. However, the 1-factor CFA model ($\chi^2_{(119)}$ = 983.842, CFI = 0.735, TLI = 0.697, RMSEA = 0.129 (90% CI 0.122-0.137), SRMR= .089), as well as the 2-factor model ($\chi^2_{(103)}$ = 546.402, CFI = 0.864, TLI = 0.821, RMSEA = 0.099 (90% CI 0.122-0.108), SRMR = 0.058) did not have acceptable fit to the data. The 3-factor model

had good fit to the data: $\chi^2_{(88)}$ = 274.769, CFI = 0.943, TLI = 0.912, RMSEA = 0.070 (90% CI 0.061-0.079), SRMR = 0.032).

Geomin rotated factor loadings are reported in table 5.1. We labeled the three factors meaning in life, life satisfaction and sense of mastery.

Table 5.1: Geomin rotated factor loadings and correlations between factors for the 3-factor ESEM solution in the calibration sample

ITEM CONTENT		F1 SENSE OF MASTERY	F2 LIFE SATISFACTION	F3 MEANING IN LIFE
1R	I can't solve some of the problems I have	0.646*	-0.035	0.020
2R	I have little control over the things that happen to me	0.722*	-0.068	-0.018
3R	I often feel helpless in dealing with the problems of life	0.730*	0.088	-0.006
4	I can do about anything I set my mind to	0.653*	0.013	0.022
5	I can determine how I want things in my life	0.618*	-0.105	0.014
6	My life has a clear sense of purpose	-0.022	0.844*	-0.026
7	I understand my life's meaning	-0.033	0.826*	0.020
8	I have a good sense of what makes my life meaningful	-0.022	0.807*	-0.018
9	I have discovered a satisfying life purpose	0.026	0.738*	0.100
10R	My life has no clear purpose	0.065	0.534*	0.096
11	I have the feeling I am included in the community	0.011	0.561*	0.090
12	I am looking forward to events in the future	0.003	0.577*	-0.067
13	In most ways my life is close to my ideal	0.002	0.102	0.710*
14	The conditions of my life are excellent	0.332*	0.026	0.499*
15	I am satisfied with my life	0.083	0.144*	0.599*
16	So far I have gotten the important things I want in life	-0.121	-0.020	0.814*
17	If I could live my life over, I would change almost nothing	-0.145	-0.009	0.739*
F1	Sense of mastery	1.000		
F2	Life satisfaction	0.556*	1.000	
F3	Meaning in life	0.585*	0.565*	1.000

R = reversed scored item, * significant at p<.05

4.2 IRT modeling in the calibration sample

Since the ESEM analyses indicated three underlying factors, we applied a multi-dimensional graded IRT model (Metropolis-Hastings Robbins-Monro Algorithm). Table 5.2 presents the discrimination values (*a* parameters) for the three dimensions. Highest discrimination values for the sense of mastery dimension were found in "I can't solve some of the problems I have"-reversed (*a*=2.15), "I have little control over the things that happen to me"-reversed (*a*=2.39) and "I often feel helpless in dealing with the problems of life"

-reversed (*a*=3.52). For the meaning in life dimension, most discriminating values were "I understand my life's meaning" (*a*=3.62), "I have a good sense of what makes my life meaningful" (*a*=3.67) and "I have discovered a satisfying life purpose" (*a*=3.51). For the dimension of life satisfaction, the most discriminating values were found for "The conditions of my life are excellent" (*a*=3.06), "I am satisfied with my life" (*a*=3.54) and "So far I have gotten the important things I want in life" (*a*=2.36). Since these three items all had substantial factor loadings on the corresponding dimensions in the ESEM analyses and no cross-loadings (i.e. pure indicators of the dimension), we decided to retain these 9 items, 3 per dimension, for our SWIO. The complete SWIO and instruction manual can be found in appendix 5.

Table 5.2: Multidimensional Graded Model Item Parameter Estimates

	ITEM CONTENT	a_1	*s.e.*	a_2	*s.e.*	a_3	*s.e.*
1R	I can't solve some of the problems I have	**2.15**	0.23	0.00	–	0.00	–
2R	I have little control over the things that happen to me	**2.39**	0.25	0.00	–	0.00	–
3R	I often feel helpless in dealing with the problems of life	**3.52**	0.44	0.00	–	0.00	–
4	I can do about anything I set my mind to	1.90	0.18	0.00	–	0.00	–
5	I can determine how I want things in my life	1.70	0.18	0.00	–	0.00	–
6	My life has a clear sense of purpose	0.00	–	3.40	0.30	0.00	–
7	I understand my life's meaning	0.00	–	**3.62**	0.33	0.00	–
8	I have a good sense of what makes my life meaningful	0.00	–	**3.67**	0.32	0.00	–
9	I have discovered a satisfying life purpose	0.00	–	**3.51**	0.29	0.00	–
10R	My life has no clear purpose	0.00	–	1.95	0.18	0.00	–
11	I have the feeling I am included in the community	0.00	–	2.09	0.18	0.00	–
12	I am looking forward to events in the future	0.00	–	1.57	0.15	0.00	–
13	In most ways my life is close to my ideal	0.00	–	0.00	–	2.32	0.20
14	The conditions of my life are excellent	0.00	–	0.00	–	**3.06**	0.28
15	I am satisfied with my life	0.00	–	0.00	–	**3.54**	0.37
16	So far I have gotten the important things I want in life	0.00	–	0.00	–	**2.36**	0.20
17	If I could live my life over, I would change almost nothing	0.00	–	0.00	–	1.52	0.14

R= reversed scored item

4.3 Cross-validation of the SWIO in the validation sample.

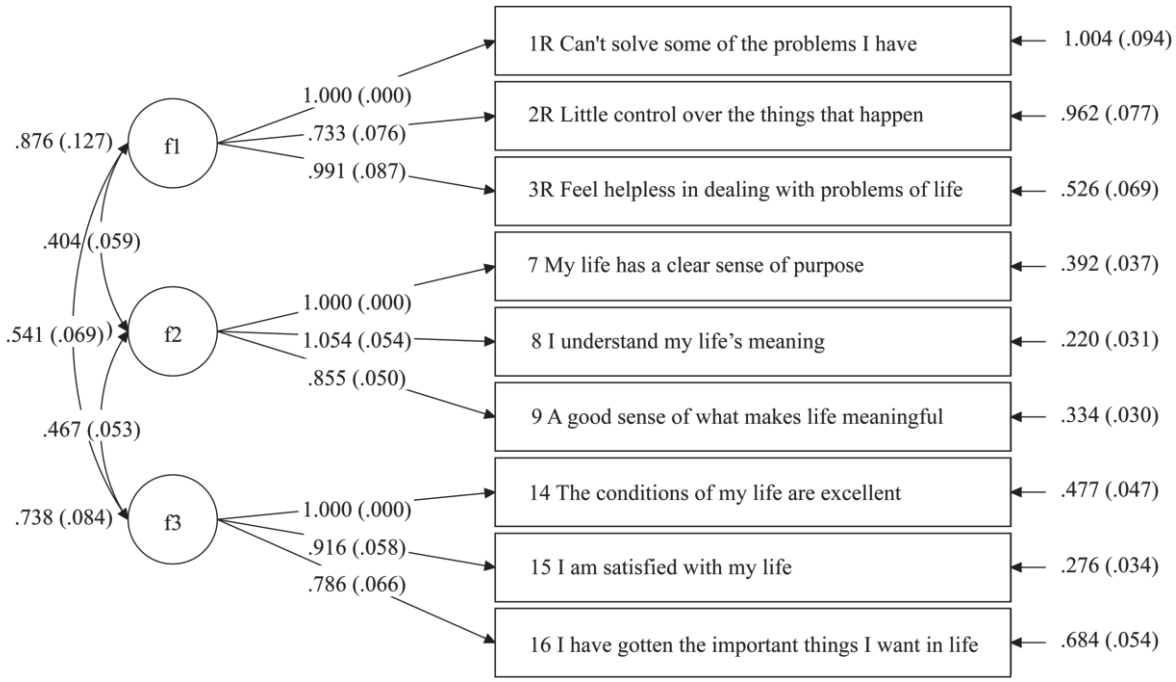
All scales showed good internal consistency (sense of mastery α=.864, meaning of life α=.715 and life satisfaction α=.782).

The confirmatory factor analyses on the 9 SWIO items results in good fit to the data ($\chi^2_{(24)}$ = 67.164, CFI = 0.973, TLI = 0.959, RMSEA = 0.064 (90% CI 0.046-0.083), SRMR = 0.041). Specified patterns and standardized factor loadings are displayed in figure 5.1.

4.4 External validity: Correlation with frailty dimensions and NRS's.

Table 5.3 presents zero-order correlations to assess the relationship between the subdimensions of well-being and the validation measures. For the frailty dimensions, all correlations were negative, and most correlations were of a medium effect size. The highest correlations were found in psychological frailty with a large correlation with sense of mastery (r=-.624) and life satisfaction (r=-.524) and a medium correlation with meaning in life (r=-.489). Cognitive frailty had a medium correlation with sense of mastery (r=-.452) and meaning in life (=-.322) and a small correlation with life satisfaction (r=-.258). Social frailty had a small correlation with sense of mastery (r=-.285) but a medium correlation with meaning in life (r=-.358) and life satisfaction (r=-.306). Physical frailty had a medium correlation with sense of mastery (r=-.395) and small correlations with meaning in life (r=-.237) and life satisfaction (r=-.259). Last, small correlations were found between environmental frailty and sense of mastery (r=-.293), meaning in life (r=-.208) and life satisfaction (r=-.256).

Figure 5.1: standardized factor loadings of the 3-factor CFA model in the validation sample



f1 = sense of mastery dimension, f2= meaning in life dimension, f3 = life satisfaction dimension

Regarding the correlation between the subdimensions of well-being and the NRS's for quality of life, meaning in life, community inclusion, all correlations were positive, and correlations for subjective frailty were negative. Most of them were of medium effect size as well. Highest correlation was found between meaning in life as a subdimension and the MIL NRS (r=.566). Further, there was a large correlation with life satisfaction (r=.528) and a medium correlation with sense of mastery (r=.435). QOL NRS had a large correlation with life satisfaction (r=.541) and a medium correlation with sense of mastery (r=.461) and meaning in life (r=.459). SOM NRS had a medium correlation with sense of mastery (r=.436), meaning in life (r=.406) and life satisfaction (r=.389). Medium correlations were also found between CI NRS and sense of mastery (r=.444), meaning in life (r=.460) and life satisfaction (r=.406). Last, for subjective frailty NRS, a medium correlation was found

with sense of mastery (r=-.370) and life satisfaction (r=-.367) and a small correlation with meaning in life (r=-.278).

5 Discussion

This study is one of the few that focused on *positive* frailty outcomes instead of *adverse, medical* frailty outcomes. Purpose of the study was to develop an instrument that measures well-being in a frail older community dwelling population. To construct such an instrument that is both short and discriminates sufficiently, a combination of factor analyses and IRT modelling was applied on a sample of 871 community-dwelling older adults with a high frailty risk profile. Sense of mastery, meaning in life, life satisfaction and community inclusion were identified as positive outcomes in earlier frailty research (Dury et al., 2018; van der Vorst et al., 2017) and were the subject matter for the development of the SWIO. For the underlying structure, ESEM was performed on a calibration sample with 14 items from existing scales and 3 self-constructed items. With regard to the factor structure of all potential well-being items, the 3-factor model had a good fit to the data and these factors were labeled as sense of mastery, meaning in life and life satisfaction. Subsequently, a multidimensional graded IRT model was applied. 3 subscales with respectively 3 items each remained for the final SWIO.

In the validation sample, the SWIO was cross-validated and all scales had good internal consistency. The CFA resulted in a good fit of the data. To establish convergent validity, the SWIO was subsequently externally validated with five frailty dimensions of the CFAI (i.e. physical, environmental, cognitive, social and psychological frailty) and the NRS's QOL, MIL, CI and SOM and subjective frailty. The SWIO was, like expected, negatively associated with all frailty domains as well as with subjective frailty, and positively associated with the NRS's. The SWIO can be used in the screening and evaluation of well-being for frail community-dwelling older adults. None of the self-constructed items were used in the final version of the SWIO. In appreciation to the researchers of the original instruments that were applied in this short instrument, the full names of the instruments, the author's names and the references to publication of the original instruments are represented at the bottom of the SWIO questionnaire and manual (see also appendix 5). The primary purpose

of the SWIO development was to evaluate the well-being of community-dwelling older adults. Since all items in the final version of the SWIO are all derived from international instruments which are used in nursing homes or geriatric care units, we also encourage its use in such settings.

Table 5.3: Pearsons correlations among subdimensions of well-being and validation measures

		1	2	3	4	5	6	7	8	9	10	11	12	13
Correlations	1. Sense of mastery†	1												
(N)		(853)												
	2. Meaning in life†	.440**	1											
		(805)	(816)											
	3. Life satisfaction†	.492**	.576**	1										
		(843)	(808)	(858)										
	4. Physical frailty	-.395**	-.237**	-.259**	1									
		(841)	(803)	(845)	(857)									
	5. Environmental frailty	-.293**	-.208**	-.256**	.126**	1								
		(838)	(800)	(843)	(840)	(852)								
	6. Cognitive frailty	-.452**	-.322**	-.258**	.401**	.213**	1							
		(839)	(802)	(843)	(840)	(837)	(853)							
	7. Social frailty	-.285**	-.358**	-.306**	.174**	.209**	.225**	1						
		(842)	(803)	(845)	(843)	(841)	(841)	(855)						
	8. Psychological frailty	-.624**	-.489**	-.524**	.357**	.329**	.418**	.354**	1					
		(841)	(804)	(847)	(845)	(841)	(840)	(844)	(855)					
	9. NRS Quality of life	.461**	.459**	.541**	-.348**	-.219**	-.300**	-.242**	-.439**	1				
		(847)	(812)	(854)	(851)	(846)	(847)	(849)	(851)	(863)				
	10. NRS Meaning in life	.435**	.566**	.528**	-.299**	-.220**	-.285**	-.303**	-.487**	.711**	1			
		(841)	(807)	(848)	(844)	(840)	(841)	(843)	(845)	(855)	(856)			
	11. NRS Sense of mastery	.436**	.406**	.389**	-.286**	-.202**	-.303**	-.261**	-.369**	.523**	.480**	1		
		(838)	(803)	(843)	(838)	(835)	(838)	(838)	(839)	(849)	(846)	(851)		
	12. NRS Community inclusion	.444**	.460**	.406**	-.285**	-.250**	-.311**	-.406**	-.431**	.542**	.612**	.475**	1	
		(844)	(810)	(851)	(846)	(843)	(844)	(846)	(847)	(857)	(852)	(848)	(859)	
	13. NRS Subjective frailty	-.370**	-.278**	-.367**	.221**	.160**	.211**	.203**	.354**	-.430**	-.441**	-.358**	-.394**	1
		(843)	(807)	(849)	(845)	(841)	(842)	(844)	(845)	(855)	(850)	(845)	(852)	(857)

**p < 0.01 (2-tailed). † Subdimensions of well-being.

This study also had limitations and, therefore, the findings should be interpreted with some caution. First, the SWIO is a brief instrument that gives an indication of frail older adult's well-being. For a more comprehensive and in-depth evaluation of well-being, other instruments such as the Flourishing Scale and the The Scale of Positive and Negative Experience (Diener et al., 2010) or other might be more appropriate. Second, next to the frailty domains, a cross-validation occurred with NRS's for QOL, MIL, CI, SOM and subjective frailty. However, these NRS's were used in earlier research (van der Vorst et al., 2017), they can't be considered as a validated measurement in contrast to the CFAI that is a validated instrument (De Witte et al., 2013). Third, the efficacy of the SWIO as an outcome measurement for treatment remains to be further explored.

6 Conclusions

In frailty research, the focus of geriatric and gerontological studies is mostly on adverse frailty outcomes rather than positive outcomes such as well-being. Overall, this study presents a short instrument to evaluate three different domains of well-being, namely sense of mastery, meaning in life and life satisfaction. By performing IRT analyses, a Short Well-being Instrument for Older adults or SWIO was developed, cross-validated and can be used for in a group of vulnerable and or frail community-dwelling older adults to identify the level of well-being.

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PART III – THE SOCIAL ENVIRONMENT: BALANCING FACTORS FOR FRAILTY AND FRAILTY OUTCOMES

Chapter 6

The Social Environment's Relationship with Frailty: Evidence from Existing Studies

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1 Abstract

Increasingly, policymakers assume that informal networks will provide care for frail older people. While the literature has mainly discussed the role of the family, broader social networks are also considered to be important. However, these social networks can diminish in later life. This systematic review investigates whether the social environment increases the risk of frailty or helps to prevent it. Findings from 15 original studies were classified using five different factors, which denoted five dimensions of the social environment: (a) social networks, (b) social support, (c) social participation, (d) subjective neighborhood experience, and (e) socioeconomic neighbourhood characteristics. The discussion highlights that the social environment and frailty are indeed related, and how the neighborhood dimensions and social participation had more consistent results than social support and social networks. Conclusively, recommendations are formulated to contemplate all dimensions of the social environment for further research examining frailty and community care.

Keywords: frailty, aging in place, social environment, later life, systematic review

2 Introduction

The aging in place concept refers to the idea that most older people prefer to stay in their local community as long as possible (Björnsdóttir, Ceci, & Purkis, 2015; Fänge, Oswald, & Clemson, 2012). Aging in the right place extends the concept that the right place to age can either be continuing to live in the same home yet also moving to a home that is more adapted to their needs while maintaining vital connections with their community, friends, and family (Beard et al., 2016; World Health Organization [WHO], 2015). This remains the case even when older people become frail and have increasing care needs (Wiles, Leibing, Guberman, Reeve, & Allen, 2012). Despite the lack of consensus on a definition or the conceptualization of frailty, most researchers define frailty as a biophysical syndrome (Fried et al., 2001) with underlying physical problems (Strawbridge, Shema, Balfour, Higby, & Kaplan, 1998) or an accumulation of deficits (Rockwood, Mitnitski, Song, Steen, & Skoog, 2006). Some scholars have criticized this unilateral biomedical approach to frailty and widened the definition to include the following frailty dimensions: psychological

(Monteserin et al., 2010), social (Gobbens et al., 2010), cognitive (Puts, Lips, & Deeg, 2005), and environmental factors (De Witte et al., 2013).

Preventing frailty is vital to avoid associated risks, such as institutionalization (Rockwood et al., 2006), poor quality of life (Masel, Graham, Reistetter, Markides, & Ottenbacher, 2009), and burgeoning public sector expenditure (Bergman, Béland, & Perrault, 2002). For example, simple inhouse adaptations can keep older people self-reliant. Additionally, new techniques of specialized health care (e.g., peritoneal dialysis at home) have been adopted by homecare services to reduce hospital visits (Findlay & Isles, 2015), and recent innovations such as eHealth and mobile health applications have, in several studies, been reported to increase the time that older people remain independent at home (Van Herck, 2015; World Health Organization [WHO], 2015).

In addition to these innovative home adaptations, for community-dwelling older people, authorities have increasingly turned to their social network and members of the community to assist with their care and support needs (Koops & Kwekkeboom, 2005). While older people prefer being cared for by informal caregivers (Eckert, Morgan, & Swamy, 2004), community care is often used to constrain public sector spending by adapting someone's social network into a source of long-term care (Keating, Otfinowski, Wenger, Fast, & Derksen, 2003).

Older people's environments have not only been of interest to policymakers, but they have also received ample research attention in aging studies. According to theories of environmental gerontology, over their life span, people are influenced by an ongoing interchange between the individual and their social and physical environment (Wahl & Oswald, 2010). Studies in environmental gerontology have tended to focus on the physical/material and the spatial components of aging, while acknowledging the links between the physical, social, psychological, and cultural environments (Peace, Wahl, Mollenkopf, & Oswald, 2007). The social environment, however, is essential for all as everyone grows up in their community (Wacker & Roberto, 2014), and it is positively related with feelings of safety (De Donder, De Witte, Buffel, Dury, & Verte, 2012), quality of life (Jia, Moriarty, & Kanarek, 2009), and general health and well-being in later life (Lehning, Smith, & Dunkle, 2014).

To age in place and maintain independence, the provision of personal care and support for older people is shifting from purely professional care to inclusive care, provided by both professionals and informal caregivers (Wiles et al., 2012). This inclusive care provision was based on a particular interest in the social environment of older people (World Health Organization [WHO], 2008). For example, new concepts such as "Age Friendly Initiatives" reflect a paradigm shift in focus from individual to community support services that promote aging in place (Greenfield, Oberlink, Scharlach, Neal, & Stafford, 2015). Environmental gerontology's theoretical insights indicate that improving the social environment of older people is expected to have a positive impact on reducing disability and loss of autonomy when people age (Wahl & Oswald, 2010). Correlations between the social environment and health have already been reviewed (Annear et al., 2014); however, the nature of the relationship between the social environment and frailty in later life remains unclear.

2.1 Objectives

To address the research gap, this article aims to systematically review existing research that has examined the relationship between the social environment and frailty. Social determinants of health have been conceptualized in many models (Solar, Irwin, & World Health Organization, 2010) and a person's social environment includes a range of social factors. In the ecological systems theory, Bronfenbrenner (1994) describes this range of factors as overlapping layers of environmental context that influences the human development (Bronfenbrenner, 1994). These layers are organized as nested structures and represent different levels of context: micro, meso, exo, and macro. Within this ecological model, a microsystem is a pattern of social roles, activities, and interpersonal relations in the immediate surrounding (e.g., family). The mesosystem describes the connection and processes between microsystems (e.g., the relations between family members and neighbors). The exosystem includes the linkages between two settings in which events occur that have an indirect influence on the individual (e.g., the socioeconomic deprivation in the neighborhood). Sociodemographic and socioeconomic elements as individual factors as well as macro factors by means of higher level economic indicators and their relation with frailty have been studied before in systematic reviews

(Gray et al., 2016; Mello, Engstrom, & Alves, 2014). Hence, the meso and exo factors were chosen as the focus of this article. In conceptualization of the social environment with these factors, definitions may vary depending on the authors' research paradigm (Van Cauwenberg et al., 2014). For instance, studies refer to social environment as neighborhood social capital (Carpiano, 2007), social circumstance (Berkman, Glass, Brissette, & Seeman, 2000), or neighborhood (Gray, 2009). Clearly, the social environment can be recognized as a multidimensional concept (Buffel et al., 2012) and research should take these different dimensions into account. Consequently, this review will investigate which dimensions of the social living environment are used in frailty research, and of these, which have a relationship with frailty.

3 METHOD

Registration

The PRISMA guidelines have been followed in this systematic review (Moher, Liberati, Tetzlaff, & Altman, 2009). This review was also registered for review in the PROSPERO database on 14 August 2015 (registration code CRD42015025097).

Eligibility Criteria

The articles selected were published in peer-reviewed journals and their main or secondary study objective was the relationship between the social living environment and frailty. Gray literature was not included in the literature search as the focus was on the current knowledge specifically related to frailty research. No minimum age was specified in defining "older people" as an inclusion criteria; however, all articles had a focus on older people. Only publications in English were included. Studies were excluded when frailty was not measured with a validated instrument or when the social living environment was only defined as "living alone."

Search

Four databases were searched for relevant articles. Advanced searches were performed in Web of Science, Proquest Social Science, and Ovid PsycINFO databases using (health OR frail* OR vulnerab* OR well-being) in title and (Frail*) AND (elder* OR "later life" OR "older adult*" OR age* OR ag$ing) AND (network OR support OR environment OR cohesion

OR capital OR relation* OR *social) in the topic or keyword of the article. A similar search was performed in Pubmed using available MeSH terms. The full search strategy and the search terms for all the databases are available online in the PROSPERO database or in appendix 6.

Study Selection

First, after duplicates were removed, a researcher screened all the records by title and relevant articles were then screened by abstract. Second, full-tekst articles were screened for eligibility and further inclusion by two researchers. Where there was no agreement, a third researcher was consulted. Third, the references and cited articles of the included studies were screened; this included all new publications until December 31, 2015, identified via email alerts sent by the included databases.

Data Extraction and Study Quality Appraisal

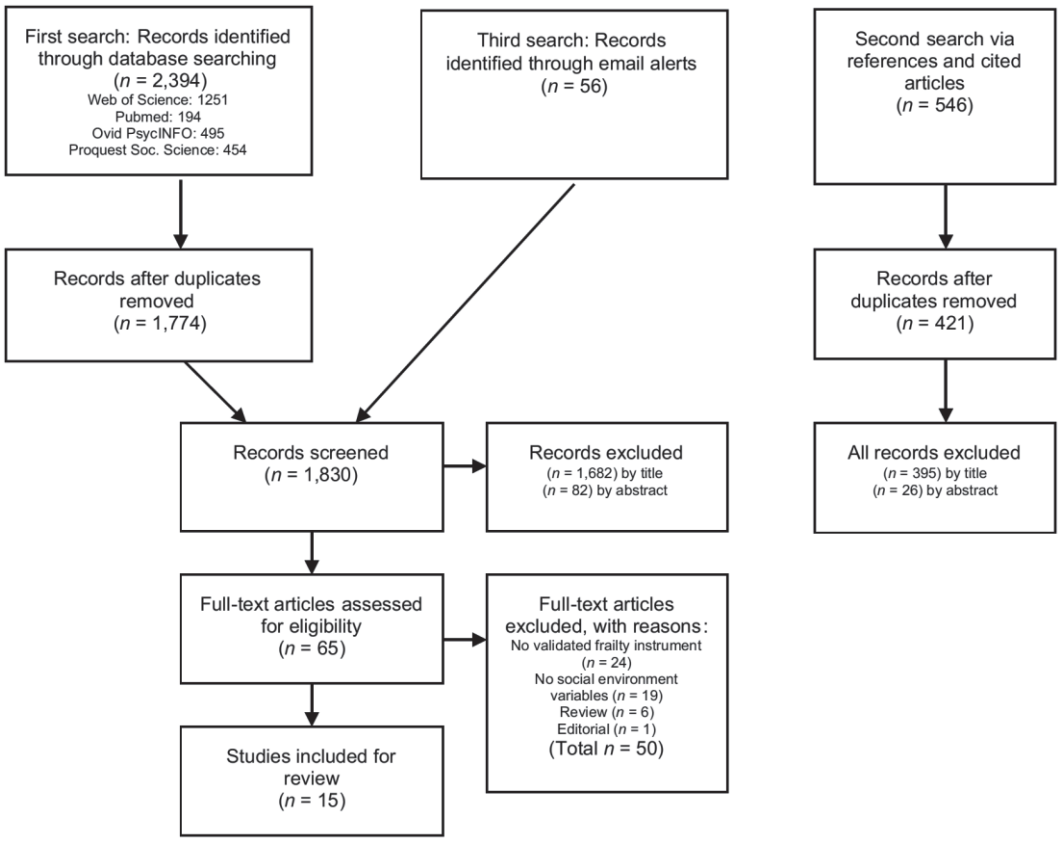
Two researchers separately categorized the study outcomes in two distinct groups. In the first group, frailty was the dependent variable and in the second, adverse outcomes of frailty. All relationships between the social living environment and frailty were analyzed and further categorized in five dimensions. These dimensions emerged from inductive classification of the data in the included articles: social network, social support, social participation, neighborhood characteristics, and perceived neighborhood experience. Three researchers discussed the names of these dimensions until a consensus was reached. The quality of the studies included in this review were appraised using six items that were adapted from the STROBE Statement checklist of items that should be included when reporting observational studies (von Elm et al., 2007).

4 Results

A flow chart illustrates the literature search process (see Figure 6.1), but can be summarized as follows: First, 1,774 original records were found in four databases on August 14, 2015, and 62 full-text articles were screened for relationships between the social environment and frailty. Fourteen articles were identified in this first stage. Second, the references and cited articles of the included studies were screened; however, this did not yield any new articles. Third, the abstracts of 56 new publications up until December

31, 2015, were screened as a result of email alerts sent by the databases. This strategy resulted in one additional study being included, resulting in 15 articles identified in total.

Figure 6.1: Flow chart summarising the literature search



Study Characteristics

Table 6.1 presents an overview of the study characteristics included. In general, all studies can be classified into two categories with regard to the study outcomes: Eleven studies had frailty as the dependent variable and four studies had adverse frailty outcomes as the dependent variable. In terms of the frailty measurements used, 13 articles used physical frailty, seven used the Fried criteria (Fried et al., 2001) to define physical frailty, four utilized a frailty index that uses a range of deficits (here 35 to 62 items), and one used the

brief instrument of frailty (Rockwood et al., 1999). (For more information on the frailty index, please see Mitnitski, Mogilner, & Rockwood, 2001 or Rockwood & Mitnitski, 2007.) One article used the physical domain of the multidimensional Groningen frailty indicator. Two articles used the Tilburg frailty indicator to operationalize multidimensional (i.e., physical-psychological-social) frailty.

The outcomes chosen for adverse frailty were functional decline or disability, functional limitations in activities of daily living (e.g., telephone use, shopping, preparing meals), health care utilization (e.g., hospitalization), receiving personal/nursing/informal care, visits to general practitioner, increased care needs on hospital discharge, emergency rehospitalization 1-month posthospitalization, lower quality of life and mortality (e.g.. at 12 months posthospital discharge). The studies were carried out in Europe (n = 7), Central/North America (n = 5), and Australasia (n = 3). Numbers of participants ranged from 172 (in a single city) to 14,082 (in a study of 11 European Union countries). Ten out of 15 studies had a longitudinal design from 12 months to 13 years, and five studies were cross-sectional. Age inclusion/exclusion criteria were different across the studies. One study only included older adults younger than 65 years, while 12 studies only included participants over 65 years and one study only included male participants. In terms of data analysis, 14 studies used regression analysis (linear, logistic, sequential, or combination) and one article used bivariate analysis. The five dimensions of social environment that appeared in the articles were social networks, social support, social participation, neighborhood characteristics, and subjective neighborhood experiences. (a) Social networks were described in terms of having family in the neighborhood, being satisfied with social relationships, and missing people when they were not around. (b) Social support was described as emotional support, instrumental/practical support, or a combination of support from family and neighbors. (c) Social participation was described as engagement in groups, leisure activities, or social activities (e.g., volunteering). (d) Neighborhood characteristics were classified as socioeconomic deprivation of the neighborhood and the percentage of persons from the same ethnic group in the neighborhood. (e) Finally, subjective neighborhood was identified as experiences neighborhood security, neighborhood social cohesion, and sense of belonging, and a combination of enjoying the home and neighborhood.

Study Appraisal

All included studies used a validated instrument to assess frailty and all dimensions of social environment were explained in the Method section of each study. Eight studies used a scale or part of a scale for measuring the social environment dimensions and all referenced their scale (Ament, de Vugt, Verhey, & Kempen, 2014; Andrew & Keefe, 2014; Cramm & Nieboer, 2013; Dent & Hoogendijk, 2014; Gale et al., 2012; Gobbens, van Assen, Luijkx, & Schols, 2012; Lurie, Myers, Goldbourt, & Gerber, 2015; Peek, Howrey, Ternent, Ray, & Ottenbacher, 2012). Andrew and Keefe (2014) use a social vulnerability index in their gerontological research. The social vulnerability index measures cumulative social vulnerabilities. In the reviewed article, these social vulnerabilities were grouped in seven factors using principal component analysis. Three of these factors (engagement, social support, and relations with others) were consistent with our social environment domains, and consequently the results of these factors were discussed in our five dimensions. The remaining factors from this index (contextual socioeconomic status, self-esteem, sense of control, and living situation) are considered as individual social factors and consequently did not fit with our conceptualization of social environment. Three studies collected official data on the socioeconomic status of the neighborhood to examine the relation between the neighborhood characteristics and frailty (Aranda, Ray, Al Snih, Ottenbacher, & Markides, 2011; Lurie et al., 2015; Peek et al., 2012).

Table 6.1: Included study synopses (alphabetical)

Reference	N participants	Age (mean)	Design (years/months)	Frailty measurement	Dependent variable	1	2	3	4	5
Ament *et al*., 2014	421	≥70 (78,1)	Longitudinal (12m)	Physical domain of the GFI	Adverse frailty outcomes	○	-	-	-	-
Andrew & Keefe, 2014	2 740	≥65 (73,4)	Longitudinal (10y)	Frailty index	Frailty	○	○	●	-	-
Aranda *et al*., 2011	2 069	≥75 (*m*)	Longitudinal (2y)	Fried criteria	Frailty	-	○	-	●	-
Cramm & Nieboer, 2013	945	≥70 (77,5)	Cross-sectional	TFI	Frailty	-	-	-	-	●
Dent & Hoogendijk, 2014	172	≥70 (*m*)	Longitudinal (12m)	Fried criteria	Adverse frailty outcomes	○	-	◉	-	◉
Etman *et al*., 2015	14 082	≥55 (*m*)	Longitudinal (2y)	Fried criteria	Frailty	-	-	●	-	-
Gale *et al*., 2012	482	*m (*64,8)	Longitudinal (4,4y)	Fried criteria	Frailty	◉	○	-	-	-
Gobbens *et al*., 2012	484	≥75 (80,3)	Longitudinal (2y)	TFI	Adverse frailty outcomes	◉	-	-	-	-
Hoogendijk *et al*., 2014	1 665	≥58 (*m*)	Longitudinal (3y)	Fried criteria	Adverse frailty outcomes	-	○	-	-	-
Lurie *et al*., 2015	558	≤65 (52)	Longitudinal (10-13y)	Frailty index	Frailty		●		○	
Kawano-Soto *et al*., 2012	927	≥70 (78,2)	Cross-sectional	Fried criteria	Frailty	○	○	-	-	-
Lang *et al*., 2009	4 818	≥65 (74)	Cross-sectional	Frailty index	Frailty	-	-	-	●	-
Peek *et al*., 2012	3 050	≥65 (75,14)	Longitudinal (12y)	Fried criteria	Frailty	-	◉	-	-	-
St John *et al*., 2013	1 751	≥65 (77,5)	Cross-sectional	Brief instrument of frailty	Frailty	-	○	-	-	-
Woo *et al*., 2005	2 032	≥70 (*m*)	Cross-sectional	Frailty index	Frailty	◉	◉	◉	-	-

TFI = Tilburg frailty indicator, GFI = Groningen frailty indicator, *m* = missing

1 = relationship between social networks and frailty, 2 = relationship between social support and frailty, 3 = relationship between social participation and frailty, 4 = relationship between neighbourhood characteristics and frailty, 5 = relationship between subjective neighbourhood experience and frailty,

● = significant relationship with frailty or adverse frailty outcomes, ○ = no significant relationship with frailty or adverse frailty outcomes, ◉ = contested relationship with frailty or adverse frailty outcomes, - = not researched

Nine studies performed analysis on data drawn from ongoing multipurpose longitudinal aging studies (i.e., The Survey of Health, Ageing, and Retirement in Europe in Etman, Kamphuis, van der Cammen, Burdorf, & van Lenthe, 2015), but failed to provide information such as response rate, study setting, or participant eligibility and selection

(Andrew & Keefe, 2014; Aranda et al., 2011; Etman et al., 2015; Gale et al., 2012; Hoogendijk et al., 2014; Kawano-Soto, Garcia-Lara, & Alberto Avila-Funes, 2012; Lang et al., 2009; Peek et al., 2012; St John, Montgomery, & Tyas, 2013). The six other studies had response rate information, of which two reported actual percentages (Ament et al., 2014; Cramm & Nieboer, 2013; Dent & Hoogendijk, 2014; Gobbens et al., 2012; Lurie et al., 2015; Woo, Goggins, Sham, & Ho, 2005). With the exception of one study, all gave a clear description of the statistical methods and participant characteristics. All longitudinal studies reported follow-up time. Only two articles described their efforts to address potential sources of bias (Andrew & Keefe, 2014; Etman et al., 2015) and only one article used a theoretical framework (Andrew & Keefe, 2014).

Relationship Between Social Environment and Frailty

All significant and nonsignificant relationships in the five dimensions of the social living environment and frailty or adverse frailty outcomes are given in Table 6.2. For the relationship with social network, seven studies were found; three relationships were significant, and seven relationships were not significant. Older people with fewer close relationships with others were more at risk of frailty (Gale et al., 2012). However, Woo et al. (2005) only found a significant relationship when frequent contact was with relatives and lower frailty rates were found among women, not men. Conversely, one study did not find any relationship between frailty and having friends or relatives in the neighborhood (Kawano-Soto et al., 2012). Moreover, frail hospitalized older people with poor social relationships had no higher probability of mortality and other adverse outcomes than frail older people with rich social relationships in the study (Dent & Hoogendijk, 2014). Likewise, when physically frail hospitalized older people were also socially frail, there was no higher risk for lower quality of life, new hospital admissions, or disability in instrumental activities of daily living (IADL) after 1 year (Ament et al., 2014).

Nine studies included social support as a potential cause or modifier for frailty or adverse frailty outcomes. For these studies, four significant and 10 nonsignificant relationships were found. For older people who were moderately frail, increased social support was associated with less-steep increases of frailty over time. On the other hand, for older people with a high frailty level, there was no significant relationship (Peek et al., 2012). Social

support from relatives was associated with lower levels of frailty for older men but not older women. On the other hand, social support from neighbors was related to lower frailty levels for both genders (Woo et al., 2005). A distinction between practical and emotional support was made in five studies. Neither emotional (Aranda et al., 2011; Gale et al., 2012; St John et al., 2013) nor practical support was related to frailty (Gale et al., 2012; Kawano-Soto et al., 2012; St John et al., 2013), or more functional decline and mortality when frail older people were hospitalized (Hoogendijk et al., 2014).

The relationship between social participation and frailty was researched in four studies; five relationships were significant and two were nonsignificant. Helping others was related to lower frailty in one study, as was attending community or religious activities, but only for women (Woo et al., 2005). Another study found a relationship between lower frailty levels and social participation, using the engagement dimension, in the social vulnerability index (Andrew & Keefe, 2014). Not participating in social life was related to a greater risk of frailty and this risk was exacerbated in older people with lower levels of education (Etman et al., 2015). Frail hospitalized older people who did few social activities had a higher likelihood of mortality and being discharged with higher levels of care. However, there was no increased likelihood of other adverse frailty outcomes such as 1-month emergency rehospitalization or longer stays in nonacute care (Dent & Hoogendijk, 2014).

Neighborhood characteristics and its relationship with frailty were researched in three studies: two reported significant results and one nonsignificant. One study found a linear relationship between

Table 6.2: Significant and non-significant associations between social environment and frailty

Significant relationships	Non-significant relationships
Social networks	
	Physical frail older people who were hospitalised are not more at risk for lower quality of life and IADL disability after one year or a new hospital admission in the next year if they are also socially frail (i.e. missing people around, feeling abandoned, experience emptiness) (Ament *et al*., 2014).
	Frail hospitalised older people with poor social relationships had no higher likelihood for mortality, discharge to higher level of care, one-month emergency rehospitalisation or longer stay in non-acute care (Dent & Hoogendijk, 2014).
	No relationship between social vulnerability in the social relationships dimension (i.e. frequency of contact with neighbours, friends or caregiving for seniors) and higher levels of frailty (Andrew & Keefe, 2014).
Older women reporting a high level of negative aspects of close relationships were more at risk for frailty compared with those reporting a low level (Gale *et al*., 2012).	Older men reporting a high level of negative aspects of close relationships were not more at risk for frailty compared with those reporting a low level of negative aspects (Gale *et al*., 2012).
	There is no relationship between frailty and having friends or relatives in the neighbourhood (Kawano-Soto *et al*., 2012).
Frequent contact with relatives was related to lower frailty for older women (Woo *et al*., 2005).	Frequent contact with relatives was not related to lower frailty for older men (Woo *et al*., 2005).
Physical frailty has a negative effect on social quality of life (i.e. relationships) (Gobbens *et al*., 2012).	Social and psychological frailty does not have an effect on social quality of life (i.e. relationships) (Gobbens *et al*., 2012).
Social support	
	No relationship between social vulnerability in the social support dimension (i.e. advice, help in a crisis, support: someone to confide in, someone to make you feel loved, frequency of contact with relatives) and higher levels of frailty (Andrew & Keefe, 2014).
	Emotional support is not related to frailty (Aranda *et al*., 2011, Gale *et al*., 2012, St John *et al*., 2013).
	Practical support is not related to frailty (Gale *et al*., 2012, Kawano-Soto *et al*., 2012, St John *et al*., 2013).

Significant relationships	Non-significant relationships
Social support	
	Emotional or instrumental support is not related with more functional decline or 3-year mortality post discharge for frail hospitalised older people (Hoogendijk *et al*., 2014).
For moderately frail older people, increased social support is related to less-steep increases in frailty over time (Peek *et al*., 2012).	For older people with a high frailty level, there is no significant relationship between social support and frailty (Peek *et al*., 2012).
Social support from relatives was related to lower frailty older men (Woo *et al*., 2005).	Social support from relatives was not related to lower frailty for older women (Woo *et al*., 2005).
Social support from neighbours was related to lower frailty for older men and women (Woo *et al*., 2005). Higher perceived social support level was related to lower frailty risk (Lurie *et al*., 2015).	
Social participation	
Higher levels of frailty are related to social vulnerability in the engagement dimension (i.e. frequent group engagement, attending religious service, physical leisure activities) (Andrew & Keefe, 2014).	
Frail older people reporting with low social activities had a higher likelihood for mortality and discharge to higher-level care (Dent & Hoogendijk, 2014).	Frail older people reporting with low social activities had a no higher likelihood for one-month emergency rehospitalisation and longer stay in non-acute care (Dent & Hoogendijk, 2014).
Lower educated older people who were not socially participating in voluntary work, caring for a sick person or participating in a sports club showed an increased risk of worsening frailty compared with those who were highly educated (Etman *et al*., 2015).	
Participation in helping other people is related to lower frailty (Woo *et al*., 2005).	
Attending community or religious activities is related to lower frailty for older women (Woo *et al*., 2005).	Attending community or religious activities is not related to lower frailty for older men (Woo *et al*., 2005).

Significant relationships	Non-significant relationships
Neighbourhood characteristics	
Older Mexican American people living in an ethnically dense Mexican American neighbourhood were less at risk of increasing frailty than those who did not (Aranda *et al*., 2011).	
There is a linear relationship between frailty and neighbourhood socio-economic deprivation (Lang *et al*., 2009).	
	Neighbourhood socio-economic status is not related to frailty risk (Lurie *et al*., 2015).
Subjective neighbourhood experience	
Feeling secure in the neighbourhood is protective against frailty (Cramm & Nieboer, 2013).	
Social cohesion in the neighbourhood and having a sense of belonging protects against frailty (Cramm & Nieboer, 2013).	
Frail older people reporting low enjoyment of their home and neighbourhood were at a higher likelihood of mortality, discharge to higher level care and 1-month emergency rehospitalisation (Dent & Hoogendijk, 2014).	Frail older people reporting low enjoyment of their home and neighbourhood had a no higher likelihood for longer stay in non-acute care (Dent & Hoogendijk, 2014).

neighborhood socioeconomic deprivation and frailty (Lang et al., 2009). Likewise, Lurie et al. (2015) found a relationship between neighborhood socioeconomic status and frailty progression. However, this result was not significant when adjusted for individual socioeconomic status, age, and health covariates. Another study found that older Mexican Americans were at less risk for increasing frailty when they lived in an ethnically dense Mexican American neighborhood (Aranda et al., 2011).

With regards to the final dimension, subjective neighborhood experience, two studies researched its relationship with frailty and three found significant results, but one was not significant. Social cohesion, neighborhood belonging, and feeling secure were protective factors against frailty (Cramm & Nieboer, 2013). The last significant relationship was found with frail hospitalized older people who reported low levels of enjoyment in their home and neighborhood. They had a higher likelihood of mortality, discharge to a higher level of care,

and 1-month emergency rehospitalization. However, they were no more likely to stay longer in nonacute care (Dent & Hoogendijk, 2014).

5 Discussion

This review builds on environmental gerontology theory by including the social environment as a crucial factor for aging in place for frail older people or those at risk for frailty. Earlier research has highlighted that human aging has been decontextualized and separated from the environment (Peace et al., 2007), and there are still only a few authors who examine the social environment in their frailty research. Fifteen studies were included in this systematic review and five dimensions of social environment associated with frailty were identified. The main finding of this article is the importance of the social environment in preventing or reducing frailty, although different dimensions of social environment have different effects.

In the included studies, the dimensions of social environment most often researched were social networks and social support. Nonetheless, these studies also showed the most inconsistent relationships with frailty in comparison with studies examining other dimensions of social environment. In contrast to other health research where social networks have been found to be important for other health-related outcomes (e.g., Barton, Effing, & Cafarella, 2015), our study demonstrates that older people without strong social or support networks (both emotional and practical), in general, are not more at risk for frailty or adverse frailty outcomes. In the reviewed articles, it was not always clear if social networks were defined as structural (e.g., contact frequency) or functional (e.g., providing support). Social and support networks interconnected, as social networks can transform into support or even caregiving networks (Keating et al., 2003). For frail older people however, it might be difficult to depend on social networks for care or support as their social networks change or diminish when people age (Fung, Carstensen, & Lang, 2001). In the literature, adverse frailty outcomes focused mainly on health outcomes. For example, Gobbens et al. (2012) were the only researchers to investigate the effect of multidimensional frailty on quality of life, and they found that physical frailty had a negative effect on social relationships, yet social and psychological frailty did not (Gobbens et al., 2012). The other dimensions of the social environment indicated totally different results.

In contrast to the social networks and social support dimensions, social participation, neighborhood characteristics, and subjective neighborhood experience appear to have a protective function against frailty (Andrew & Keefe, 2014; Cramm & Nieboer, 2013; Etman et al., 2015; Woo et al., 2005), this is in addition to several adverse frailty outcomes (Dent & Hoogendijk, 2014). The differences in results are more notable when subgroups of older populations were analyzed in the reviewed articles. For social networks and support dimensions, the differences suggest that outcomes vary depending on gender and level of frailty. The beneficial effects of social networks are greater for older women (Gale et al., 2012; Woo et al., 2005), and older men with greater social support have lower levels of frailty (Woo et al., 2005). Contrastingly, Lurie et al. (2015) examined adults less than 65 years of age, and found an association between social support and lower frailty levels 10 to 13 years later. On the other hand, this study found no relationship between neighborhood characteristics and frailty, while the studies with older people did. These differences illustrate the importance of investigating frailty at an individual level, which was lacking in the majority of the studies.

This study was the first to search for relationships between frailty and the broad social environment, and it provides new insight in how to prevent frailty in the community. However, important limitations of this study should be noted. First, social environmental factors were only recently included in frailty studies. Despite the fact that relationships between social factors and frailty have previously been studied, only 15 studies were found to have researched the relationship between frailty and the social environment. Second, our search strategy and inclusion criteria only yielded cohort studies, no controlled trials were found. Furthermore, to categorize findings into significant and nonsignificant associations, the very small number of qualitative studies found were excluded. However, the decision not to include qualitative research does not mean qualitative research is not valued here. On the contrary, qualitative research could generate new research questions and explain the differences in the findings of this study in future research (Neuman, 2011). Finally, some studies analyzed their findings using secondary data and gave inadequate information about participant selection and used different or even modified versions of frailty instruments. Hence, a rather pragmatic approach for quality appraisal was taken, instead of risk of bias assessment using the Cochrane Risk of Bias Tools (Higgins & Green,

2008). The outcomes of these assessments were used to make comparisons between studies, and no study was excluded because of the low level of study reporting.

With the results of this review, some new research questions arise. Social networks and social support had in general no relationship with frailty. Only in specific cases (e.g., when the source of social support was investigated) a relationship with frailty was found, and even then there were differences between men and women. The networks of older adults are very diverse, even when they are frail (Op het Veld et al., 2015). The association between social connectedness and age is complex. Moreover, it is also dependent on several life-course factors. As networks are dynamic and move through time, space, and the life course (Fiori et al., 2007), more research in that area is needed. Apart from the association with social domains, the life course also affects the individual's health in later life. Previous research indicated that childhood disadvantages have a long-term effect on frailty trajectories (Xu, 2015). Socioeconomic disadvantage has been linked with higher allostatic load (Robertson, Popham, & Benzeval, 2014), also known as "the wear and tear" of the body. This allostatic load in turn is related to frailty (Gale, Booth, Starr, & Deary, 2016). The relationship with these individual factors was not included in this study although biological, behavioral, and psychosocial processes in the life course are shaped by both individual and environmental characteristics. In the new WHO World report on aging and health, the emphasis is on a life-course approach as the diversity in the capacities of older adults is rooted in events during the life course (Beard et al., 2016; WHO, 2015). Therefore, this life-course approach needs more attention in further research.

This review demonstrated that it is important to contemplate all dimensions of the social environment. In addition, it indicates that the older population is heterogeneous, and whether older people benefit from larger social networks or more social support depends on their gender and/or age. Although the number of articles examining neighborhood and social participation dimensions were lower than those investigating network and support dimensions, the positive results of the former imply attention for further research to proceed on policy recommendations. For example, given the impact that social participation has on frailty, establishing and supporting local policy initiatives could be a way to prevent frailty experienced by older citizens. Thus, this study is useful to better

understand the relation between frailty and the social environment and that the social profile should be systematically assessed and taken into account when evaluating older adults. The study further proposes to include a combination of social environment domains for other research examining frailty and community care, for the development of pilot interventions and controlled trials in the field.

6 Conclusion

The social environment is a broad concept that includes social networks, social support, social participation, neighborhood characteristics, and subjective neighborhood experiences, and there is evidence of relationships with frailty in later life. Social participation and neighborhood factors have a protective or balancing function in the frailty levels of community-dwelling older people. However, the relationship between frailty, social support, and social networks is contested. It is recommended that in the research for community care and prevention programs that target frailty in later life, a broad approach to the social living environment is taken.

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Chapter 7

Social Participation in the Daily Lives of Frail Older Adults: Types of Participation and Influencing Factors

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1 Abstract

Introduction: The advantages of social participation in later life are well-researched, and have been adopted in aging policy frameworks such as Age-Friendly Cities and Communities. However, little is known about the social participation of very frail older adults. This article examines the different ways in which this population participates in society, and the factors influencing this participation.

Method: Interviews with 38 very frail older adults were analyzed using Levasseur et al.'s (2010) taxonomy of activity levels. We employed a qualitative hybrid approach employing inductive and deductive thematic analysis.

Results: Participants disengaged from some activities, although they engaged in other activities on different levels. Low-key participation emerged as important for neighborhood participation. The key factors that influenced social participation were functional decline, and a changing social/physical environment. Also, social environmental factors, such as the presence of community centers, stimulated social participation.

Discussion: The results of this study advance our knowledge of the different ways frail older adults participate in society. Focusing on the social environment in Age-Friendly Cities and Communities frameworks will benefit these individuals.

Keywords: low-key – social environment – age-friendly – qualitative research

2 Introduction

Social participation is a very broad concept that can take many forms, including leisure activities, meeting friends, volunteering, and more (Levasseur, Richard, Gauvin, & Raymond, 2010). Empirical gerontological research has shown positive relationships between social participation and lower frailty levels, and between social participation and less adverse frailty outcomes. Despite the consideration of researchers to include social participation in frailty research, to date, the body of literature on different types of participation in research on frailty is poor (Duppen, Van der Elst, Dury, Lambotte, & De Donder, 2017). Given the multifaceted appearance of social participation, this study concentrates on the different ways in which frail older adults participate in society.

Current aging policy frameworks promote social participation to target the challenges of an aging society. One strategy that has been promoted by the World Health Organization (WHO) is that of age-friendly communities. Older adults can age actively in a community that optimizes "opportunities for health, participation and security in order to enhance quality of life as people age" (WHO, 2007, p. 1). The WHO concept of age-friendliness enabled researchers to investigate the effects of an age-friendly environment perspective that is now implemented worldwide through local and regional policies (Moulaert & Garon, 2016). The strategy of age-friendliness was originally developed for city policies but later adapted into age-friendly community initiatives in more rural places (Menec et al., 2014). Although Age-Friendly Cities and Communities (AFCCs) initiatives are targeted towards older adults, the concept includes all ages and is meant to be more than just elder-friendly (Fitzgerald & Caro, 2014). Improvement of the physical environment, for example, also benefits less mobile people, and secure environments stimulate children to participate in activities in their neighborhood (WHO, 2007). AFCCs illustrate the paradigm shift in aging policy from a rather individual-oriented approach by public authorities and programs for older adults, towards community support services (Greenfield, Oberlink, Scharlach, Neal, & Stafford, 2015).

As well as these benefits and opportunities, there are also challenges in creating age-friendly environments, and some have criticized the concept. One such criticism is focused on the impact on all age groups. "Are age-friendly communities intended to help healthy older people live more meaningful lives or to help the most frail older people age safely in place?" (Golant, 2014, p. 11). A second criticism concentrates on the lack of attention towards the social aspects of aging in the age-friendly literature (Smetcoren et al., 2018). The present research will address both criticisms by focusing on frail older adults and their social environment by means of social participation. The concept of AFCCs was built on the WHO's framework of active aging (WHO, 2007). The terms age-friendly and active aging are derived from an ecological perspective on aging and suggest the link between individuals and their environment, both social and physical (Steels, 2015).

Since 2015, the WHO has replaced the concept of *active aging* with that of *healthy aging* as the basis for the lead policy framework (Beard et al., 2016). This framework builds

further upon the 2002 active aging framework, emphasizing maintenance of high functional ability in later life. The new framework has been advanced taking into consideration functional ability (i.e., abilities that allow people to age well, such as meeting their own basic needs or moving around) and intrinsic capacity (i.e., all physical and mental capacities of an individual combined), which vary over the life course (WHO, 2015). In contrast to the active aging framework, where participation was one of the pillars next to health and security, this is less apparent in the new health policy framework. As an alternative, the healthy aging framework uses *needs* and captures health services, long-term care and environment as important factors in healthy aging. Social participation is included in the environmental needs, and one of the strategies is "to remove barriers to participation" (WHO, 2015 p. 33). Social participation is a key element in aging theories. The theory of disengagement was one of the first gerontological theories in 1961 that described the abandonment of social roles. Although a direct link with social participation is absent, the theory outlines that after retirement men 'should' disengage from their instrumental role (i.e., labor participation) and women detach from their socio-emotional role (i.e., marriage and family) in order to achieve fulfilling lives. Although most people disengage from the former activities to some extent, the theory was and is still very controversial (Achenbaum & Bengtson, 1994). In the same era, other researchers argued against this theory that older adults have higher levels of life satisfaction when they remain highly active instead of disengaging from activities (Marshall, Martin-Mathews, & McMullin, 2016). Today, activities for older adults are seen as crucial for building and maintaining relationships which is essential for healthy ageing (WHO, 2015).

Using the same line of reasoning, Tornstam's gerotranscendence theory is often considered as a form of negative disengagement by social gerontologists. Tornstam describes his theory as a "shift in meta-perspective from a materialistic and rational view to a more cosmic and transcendent one, normally followed by an increase in life satisfaction" (Tornstam, 1989, p. 55). The shift in meta-perspective can include decreasing interest in material things and superfluous interactions (Tornstam, 1989). This links with the socioemotional selectivity theory by Carstensen and colleagues, where the role of time predicts the goals that people attempt and the social partners they need for these goals (Carstensen, Isaacowitz, & Charles, 1999). A similarity in these aforementioned theories is

the slow decrease in the number of activities when aging (Adams, 2004). Different authors distinguish different dimensions in social participation, such as formal versus informal participation (e.g., Guillen, Coromina, & Saris, 2011), community involvement versus individual relationships (Amagasa et al., 2017), or formal participation and social activities (Buffel et al., 2014; Dury et al., 2016). A systematic review by Levasseur and colleagues (2010) differentiated six levels of activities. Doing activities alone (level 1) or in parallel (level 2) are not considered as social participation. The other levels include interaction with others and are regarded as participation: Level 3 concerns socially-oriented activities (e.g., talking with neighbors) and level 4 involves task-oriented activities (e.g., computer classes in the senior center). Level 5 activities are oriented toward helping others (e.g., volunteering), and level 6 includes society-oriented activities (e.g., being involved in a political party). Levasseur et al. stated that social engagement (levels 5 and 6) is also social participation. However, not all types of social participation (e.g., leisure activities) can be labeled as social engagement (Levasseur et al., 2010). In our study, we considered social participation to include all activities where people interact with another, from socially-oriented activities to society-oriented activities.

The advantages of social participation in later life are well-researched. These advantages include health benefits (e.g., Kim, Kim, MaloneBeach, & Han, 2016), less cognitive decline (Tomioka, Kurumatani, & Hosoi, 2016a), better quality of life (Levasseur, Desrosiers, & Tribble, 2008; Zhang & Zhang, 2015) and being able to live longer independently at home (Tomioka, Kurumatani, & Hosoi, 2016b). A recent systematic review noted a positive relationship between social participation and lower frailty levels (Duppen et al., 2017). However, there is a paucity of research on this topic, and given the different types of social participation by frail older adults, more research on the forms social participation could increase our insight into their relationship with frailty.

Building on the gerotranscendence and socioemotional selectivity theories, the inclusive purpose of AFCCs for all older adults and to gain more insight in the relationship of social participation with frailty, this study explores frail older adults' participation in social activities. The study aimed to answer two research questions:

1. How do frail older people socially participate in the society?

2. Which factors influence frail older people's social participation, and what is the role of the social environment in this process?

3 Method

3.1 Research Approach and Data Collection

The data collected in this qualitative study were based on interviews with frail community-dwelling older adults, collected in a larger study using a mixed method design (Dury et al., 2018). In this study, older adults at risk of frailty (n = 121) were interviewed by 6 researchers (92 interviews) and 3 undergraduate students (29 interviews) during the winter of 2015 – 2016. On average, the interviews lasted 46 minutes (range 17'-139') and no incentives were provided. In general, the larger study aimed to examine how older adults perceived their frailty, quality of life, sense of mastery and meaning in life, and the balancing factors that influenced these variables, such as social participation and environmental factors. The study also explored old-age life events that affected participants' experience of frailty. The results of the larger study can be found in Dury et al. (2018) and Van der Vorst et al. (2017). The topic list of the interviews was developed together with the entire D-SCOPE research group, which consisted of 21 researchers in several disciplines (e.g., neurology, general practice, psychology, educational sciences, etc.), although all researchers were specialized in gerontology, dementia and/or frailty. To extend the reliability of the interviews (Boeije, 2010), the researchers who conducted the interviews received training with simulated patients while being recorded, and practiced the interview with three simulated patients.

In the present study, a secondary analysis was carried out on the data of 38 participants who scored high on the Comprehensive Frailty Assessment Instrument (CFAI; De Witte et al., 2013).

3.2 Participant Recruitment and Characteristics

Participants were recruited in the Flemish speaking area of Belgium and the city of Brussels, Belgium, using snowball sampling. Half of the participants were recruited with the help of five home-care organizations. Participants were excluded from the study in cases of hospitalization, when the participant or the informal caregiver indicated that the

older adult was unable to participate, or when the interviewer noted that the older participant was unable to provide adequate answers.

From 121 participants in total, 39 scored as highly frail, compared to 34 who scored as mildly frail and 38 who scored as low in frailty or not frail. Ten participants ignored certain items on the self-assessment and thus had no frailty score. One person refused to participate in the qualitative interview, leaving 38 out of 121 participants eligible for this study. Table 7.1 presents an overview of the participants' characteristics. Twenty-six participants were female, 12 were male, and the mean age was 77.7 years (range 60–94). Four participants had a migration background (other country of origin than Belgium), 34 were Dutch-speaking, and one was French-speaking. An interpreter was present at the time of the interview for one Italian-speaking participant and two Turkish-speaking participants.

Table 7.1: Characteristics of participants.

Code	Age	Sex	Marital status [c]	Total	Cog	Psy	Phy	Soc	Env
R1	84	Female	Widowed	++	++	++	+	-	++
R2	85	Female	Married	++	++	+	+	+	+
R3[a]	81	Female	Widowed	++	++	++	+	+	+
R4[a, b]	81	Female	Widowed	++	++	++	++	++	+
R5[a, b]	66	Female	Widowed	++	++	++	++	++	-
R6[a, b]	61	Female	Widowed	++	++	++	+	-	-
R7	81	Male	Widowed	++	++	+	+	+	+
R8	86	Female	Widowed	++	++	++	+	-	-
R9	81	Female	Widowed	++	++	++	+	+	+
R10	81	Female	Widowed	++	++	++	++	++	++
R11	83	Male	Widowed	++	++	-	++	-	++
R12	66	Male	Divorced	++	++	++	++	-	+
R13	75	Female	Divorced	++	++	++	+	++	++
R14	79	Male	Divorced	++	++	++	+	++	++
R15	60	Male	Widowed	++	++	++	+	-	+
R16	91	Female	Widowed	++	++	+	+	++	+
R17	78	Female	Married	++	++	+	+	++	+
R18	85	Female	Widowed	++	++	++	++	+	+
R19	82	Male	Divorced	++	++	+	++	+	+

Table 7.1: Characteristics of participants *(continued)*.

Code	Age	Sex	Marital status [c]	Total	Cog	Psy	Phy	Soc	Env
R20	72	Female	Widowed	++	-	+	+	++	++
R21	80	Female	Widowed	++	++	+	++	+	++
R22	*m*	Female	Never married	++	++	-	++	-	++
R23	86	Female	Widowed	++	++	++	++	-	++
R24	93	Female	Widowed	++	++	++	+	+	-
R25	84	Male	Divorced	++	++	-	+	+	+
R26	94	Female	Widowed	++	++	-	++	+	+
R27	78	Male	Widowed	++	++	+	+	++	+
R28	89	Female	Never married	++	+	++	++	++	++
R29	76	Male	Never married	++	++	+	++	+	++
R30	94	Female	Widowed	++	++	-	++	-	++
R31	74	Female	Never Married	++	++	++	++	++	++
R32	75	Male	Widowed	++	++	++	-	++	+
R33	69	Female	Divorced	++	++	++	++	+	++
R34	80	Female	Widowed	++	++	+	++	+	+
R35	80	Female	Widowed	++	++	++	++	+	+
R36	72	Male	Widowed	++	++	++	+	+	++
R37	92	Female	Widowed	++	++	++	+	++	+
R38	79	Male	Widowed	++	++	+	++	-	-

[a] = migration background, [b] = interpreter present at the interview, Soc = social frailty, Cog = cognitive frailty, Psy = Psychological frailty, Phy = physical frailty, Env = environmental frailty. [c] marital status as official registered, it was nonetheless possible for never married, divorced and widowed persons to have a partner, which is not registered here.
Total = Total frail, ++ = high frail, + = mild frail, - = no – low frail, *m* = missing

3.3 Interview Scheme and Data Analysis

All interviews were digitally recorded with the participant's permission and transcribed verbatim. Each interview opened with the question "How do you experience frailty and what does frailty mean to you?". Depending on the participant's answer, the interviewer went into greater detail, for example on activities, former activities, and neighborhood participation. Subsequently, the other questions followed. For more information on the entire study design, see Dury et al. (2018).

A hybrid approach of inductive and deductive thematic analysis was used, as discussed by Fereday and Muir-Cochrane (2006). For the deductive analysis, the taxonomy of activity

levels by Levasseur (2010) was used a priori in the development of the code manual. Given that only the activity levels 3 to 6 are considered social participation, only these were included in the analysis. These are in more detail: level 3:socially oriented activities, such as interacting with others while receiving care, visiting friends and neighbors and having meals in a local service center; level 4: task-oriented activities, such as group activities organized by the local service center, hobby clubs and senior organizations; level 5: activities are oriented toward helping others helping others and volunteering; and level 6: includes society-oriented activities, such as being involved in an organization or political party. These are the main levels, but as the interviews progressed new themes emerged, and inductive analysis was led to the creation of sublevels.

Two researchers, who also interviewed the participants, were involved in the coding process. In the first step, they separately coded six identical interviews for the development of a code manual. Frequently occurring sublevels, such as reasons to stop, reduce or compensate for participation, were added to the code manual. One researcher coded the other interviews with the final code manual using MAXQDA software. The stages of data coding delineated by Crabtree and Miller (1999) – reading the text, creating the code manual, computer coding, sorting segments and making connections – were used as guidelines in this procedure. After this interpretive process (coding), findings were discussed with three other researchers. One of them was involved in the development of the code manual to increase credibility and to foster reflexivity, findings from the deductive analysis and new insights from the inductive analysis were discussed with two other researchers that didn't participate in the interviews. In the final step, all researchers involved in this study discussed and weighed the interpretations ('investigator triangulation,' Patton, 2015: 316).

3.4 Ethical Approval

The D-SCOPE study was approved by the Human Sciences Ethical Commission of the Vrije Universiteit Brussel (ECHW_031). All participants signed an informed consent agreement.

4 Results

4.1 Social Participation by Frail Older Adults

With respect to the levels of activities (Levasseur et al., 2010), most activities mentioned by participants were centered around the third and fourth levels (interacting with others, and doing an activity with others, respectively). Interaction with others was found to be a source of joy and quality in their lives.

Level three activities were mostly found in visiting others, receiving visitors or receiving help from professionals and family. A specific type of spontaneous participation was labeled as low-key participation. This type of participation related to daily casual contacts with neighbors and passersby in the neighborhood. These moments could be brief and were necessary for being up-to-date on everything that is happening in the neighborhood. In certain cases, there was no direct contact with the other, as an older widowed woman told:

> *I don't feel lonely... I walk around with my cane and when I look through the window, I see many people passing by (Widow, 91 years old).*

As for level four activities, many participants enjoyed going out with other people during weekly activities, such as doing groceries or occasional shopping trips with friends or family. Frequently mentioned organizers of activities were hobby clubs, senior clubs and the local service centers. According to the participants, these organizations stimulated them to stay active in ordinary activities, such as going to the movies or playing cards, as well as in extraordinary activities, like information meetings on public transport for older adults.

There were no mentions of activities that contributed to society (level six) and only two participants mentioned activities where they were helping (level five) other older adults.

> *I don't need it (help) yet, in contrast to those upstairs, two older, older than me... But I help them. I do the groceries.*

[…]

The neighbor is 88. In the morning, I go down to pick up his newspaper and I bring it up. If he needs something, groceries, I do it (Widower, 78 years old).

4.2 Factors that Influenced Frail Older People's Social Participation

Frail older adults withdrew from activities as a result of functional decline and/or a changing physical and/or social environment. Functional decline had an enormous impact on participants' mobility. Pain, experiencing balance problems, and having a slower reaction time led to fear of using public transport or walking around in the community. Visual problems caused this 79 year-old widower to stop his fishing hobby:

R: I enjoyed fishing so much, I had to get rid of everything. I couldn't see my fish dobber anymore. "How is this possible, you had an operation?", my nephew asked. But, yeah, they told me (in the hospital) they couldn't do much anymore. (…) I stopped going since.

Interviewer: Are you still in contact with people from the club?

R: No, no, no, I'm not.

The quote above illustrates how people disengage from hobbies due to functional decline. In certain cases, participants resigned themselves over the fact that they were old, and their activities belonged to the past. Others compensate the loss of one activity with another one.

We used to go cycling, now it's only here and there … It's still difficult, we used to go cycle through and around the whole of Brabant [province]. I try to cope with it by driving to people I know, to chat for an afternoon. That's how I solved that problem. (Widower, 83 years old)

As well as hobbies and other activities, shopping was an important activity for most older adults for food provision and social contact. A changing physical and or social environment such as the disappearing of local stores, difficulties in taking public transport, and heavy traffic, was responsible for the decline in neighborhood participation. According to a few participants, migration was another factor causing decline in neighborhood participation. Some had a negative image towards neighbors with a migration background, while others found that language was a barrier to connect with immigrants, just like they experienced difficulties connecting with younger adults.

An environmental cause of diminishing activity was the decline of social networks. In some cases, the death of a spouse was responsible for the loss of an entire friendship network. Peers also experience functional decline and stop visiting. Again, for some participants, these events are part of aging. One participant tried to establish new friendships to compensate for the loss of friends, but found it hard to maintain these relations due to physical problems:

> *You belong less and less somewhere, I become aware of that. I lost my best friends. Death, disease. Then I tried to build new friendships, but once you start having problems, you can't have dinner together, you can't join activities, you feel you lose them again. (Never married woman, 74 years old)*

Some participants were dreaming about taking up new or old activities. For those who did not compensate for a loss in participation, a desire for connecting with others was expressed a number of times. Again, it was not easy to make this connection. For single older adults, it appeared to be a hard step to join a group with couples and people who already knew each other.

Social environmental factors such as places in the community were people meet, the formal or informal network were found to maintain and increase frail older adults' wellbeing and act as a catalyst for social participation, as it were. The sort of activity appeared to be less important than the social contacts obtained. For one woman, making contact with others was the reason to go back to church. Another example is the role of professional

caregivers, which went beyond providing physical care alone. During care moments, they created a pleasant atmosphere in the recipient's life and were a source of information. Another example is how caregivers stimulated participation by referring lonely older adults towards community centers:

> *R: The service center, I started to go there this year, I had to.*
> *I: How come?*
> *R: My general practitioner told me to go, because I cried here all-day long. I didn't eat anymore. My husband died and I ate only sandwiches with syrup for two years. My food didn't [have] taste, it didn't taste. And now I eat there every Thursday but alone it doesn't [have] taste.*
> *I: So, your general practitioner told you to go there?*
> *R: Yes, he told me, but it's only once a week, that's not enough. Three times a week would be better, because people really look forward to that day. (Widow, 80 years old)*

When social participation declined and was more concentrated on people in the vicinity, participants greatly appreciated good contact with neighbors, both for contact and as a safety net. They told how local community centers enabled participation as well as opportunities for engagement. The participants appreciated the broad range of activities they provided, from physical activities and leisure activities to providing meals, all of which stimulated social contact.

5 Discussion

The aims of the current study were to explore: 1) how frail older people reason about and experience their social participation, 2) to generate knowledge on factors that influence frail older people's social participation, and the role of the social environment in this process. Using a hybrid approach of inductive and deductive thematic analysis, this study illustrated that despite being frail, most older adults in this study still participated in a range of activities. For these activities, the taxonomy of activity levels by Levasseur (2010) was

used to gain insight into frail older adults' social participation. To a limited extent, a few older adults in our sample participated in helping other older adults. Participating in social activities, whether organized or not, and visiting friends and family, were frequently mentioned by participants and were a source of enjoyment. Also, spontaneous or low-key social participation occurred, comprising brief contact moments with neighbors or passersby that were part of daily life. Low-key participation was earlier described in German studies (Kaspar, Oswald, & Hebsaker, 2015; Nauman, 2006) and appeared in the narratives to be important in producing a feeling of belonging in the neighborhood. Earlier frailty research on social participation included generally higher levels of social participation, such as volunteering (Etman, Kamphuis, van der Cammen, Burdorf, & van Lenthe, 2015) or engagement in helping others (Woo, Goggins, Sham, & Ho, 2005). Although this study is qualitative, and we did not want to quantify the results, we noticed that the type of activities frail older participated in are centered around lower levels of social participation and further research should take these lower levels also into account.

Regarding the second research question, functional decline and social environmental changes emerged as barriers to participation in the narratives of this study. Also, physical environmental factors that impeded participation included inaccessible public transport and heavy traffic. The ability to be mobile is an important factor for healthy aging and many cities have projects aimed at stimulating mobility by creating accessible environments, and have created initiatives to enhance public transportation (WHO, 2015).

Being able to go to local stores is another important factor in healthy aging. This basic activity is necessary for nutrition (WHO, 2015) and although the activity can be delegated to others, participants in this study found it essential for their neighborhood participation. The age-friendly concept is already embedded in businesses in several age-friendly networks. Examples of this are the education of business-serving organizations in New York, USA, to maximize both the social and economic participation of older adults (Goldman, Owusu, Smith, Martens, & Lynch, 2016), and the dementia-friendly community project in Bruges, Belgium, where a range of shop owners empathically welcome persons with dementia (Biggs & Carr, 2016).

Physical and/or social environmental factors advance leisure activities and stimulate the formulation of social networks (Wahl & Weisman, 2003). The results of this study indicated that the social environment can act as a catalyst in stimulating new or other forms of social participation for those who have fewer participation opportunities as a result of being frail. Churches and community centers were places in the nearby living environment that enabled social participation. Professional caregivers, neighbors and passers-by facilitated social participation for those with a social life that was close to, or restricted to, the home environment.

These results show that older adults do disengage from social participation when becoming frail. However, the compensation of lost participation with new forms of participation, and the stimulation provided by the social environment, can improve the wellbeing of frail older adults when they disengage from former activities. The question remains as to whether the social environment can stimulate all older adults who disengage from activities, and the limitations of this when a person is, in fact, too frail to participate in activities with others.

The results of this study did not clearly align with either gerotranscendence theory or the socio emotional selectivity theory. However, some of our findings fit within the compensation part of the theory of selection, optimization, and compensation (Baltes & Baltes, 1990). Recent research showing how compensation strategies for lost activities are important for older adults with physical impairment (Carpentieri, Elliott, Brett, & Deary, 2017) are in accordance with our findings on the compensation of lost activities for frail older adults. Our results also emphasize the importance of the role of the social environment in stimulating this compensation.

Concerning the important role that the community plays in the lives of older adults (Provencher, Keating, Warburton, & Roos, 2014) and the policy focus on healthy aging, these results indicate that a focus on the environment, and more specifically the social environment, is important for the inclusion of frail older adults in the community. However, the social environment cannot be separated from the physical environment and both should always be taken into account. As seen in these results, community service centers

can play a major role in connecting frail older adults through participation. Assuming these services are available for the frail older adult, people in the living environment can stimulate older adults into going there. AFCCs are important for frail older adults (Cramm, Van Dijk, & Nieboer, 2016). We believe that a focus on the social environment in AFCCs will increase social participation, even it is only low-key, since older adults who feel involved in their living environment and have frequent contact with people in their neighborhood are more likely to participate (Buffel et al., 2014).

Our findings must be interpreted with caution and several limitations need to be acknowledged. First, this study is a secondary analysis of interviews that were conducted to answer a broader range of research questions related to frailty in later life. In order to overcome this limitation, we 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). A second limitation of the study is the inclusion of older adults with possible cognitive impairment. The home-care organizations that were partly responsible for the recruitment of the participants in this study were asked not to refer to participants with moderate or severe dementia. The CFAI assesses subjective cognitive complaints to determine cognitive frailty and higher scores of cognitive frailty which are associated with cognitive impairment (De Roeck et al., 2018). Conclusively, some of the participants might have had mild cognitive impairment or mild dementia. However, we believe that an impaired cognitive status of the participants was associated with the quantity of data in the interviews but not an issue for the content of the responses from respondents. Third, given the vulnerable situation of the target group, a relative was allowed to be present during the interviews when requested by the participant. This is a possible source of bias as it might have encouraged socially desirable responses. Finally, we used open-ended questions in our interviews about the influence of frailty on participation and the role of the environment, and did not ask specifically about elements that are used in the described theories or models. Quantitative or qualitative studies on that topic can provide more information on this matter. The key strengths of the study are the focus on frail older adults, and the specific focus on their social participation. While some earlier quantitative studies on frailty already included a single type of social participation, such as social activities

(Dent & Hoogendijk, 2014), this study is the first to include different types of social participation in a frail population.

In conclusion, this qualitative study was designed to gain insight into how frail older adults reason about their social participation and the factors that influence this social participation. Our findings show that due to functional decline and changing environments, older adults can disengage from former activities. However, they compensate these activities with other activities or are stimulated by their social environment in up taking other activities. Age-friendly policies that focus on the social environment aligned with the physical environment are crucial for healthy aging in frail older adults and their inclusion in the local environment.

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Chapter 8

Well-being and Frailty in Later Life in a Person-Environment Fit Model

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1 Abstract

Frailty in later life research predominantly focuses on adverse health outcomes. The relationship of frailty with environmental factors and well-being is poorly understood. The present cross-sectional study addresses both within a P-E fit perspective. 869 community dwelling older adults with a frailty risk profile participated in the study. Results indicate that levels of sense of mastery, meaning in life and life satisfaction decrease with frailty and increase with a better physical and social environment. Few negative interaction effects were found, indicating both frail and non-frail older adults have higher well-being when living in a better social or physical environment.

Key-words: frailty, social environment, physical environment, person-environment fit, environmental gerontology

2 Background

Frailty in later life is associated with adverse outcomes such as institutionalization which increases public sector expenditure (Bergman, Béland, & Perrault, 2002). Therefore, governments are implementing proactive care approaches in order to delay or to prevent frailty, its adverse outcomes and to stimulate older adults to age in place (Scharlach, 2011). To date, there is no consensus on a conceptual or operational definition of frailty (Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010; Morley et al., 2013; Rodríguez-Mañas et al., 2013). Although frailty is originally mainly approached as a physical issue (Morley et al., 2013; Rodríguez-Mañas et al., 2013), different researchers argue to operationalize frailty as a multidimensional concept including the physical domain of frailty as well as a psychological, cognitive, social and an environmental domain (Armstrong, Stolee, Hirdes, & Poss, 2010; Bergman et al., 2007; De Roeck et al., 2018; De Witte et al., 2013a, 2013b; Gobbens et al., 2010).

Despite the absence of a conceptual or operational definition, researchers agree on at least two terms: A first agreement is that physical frailty as well as multidimensional frailty is a dynamic concept (e.g. Gobbens et al., 2010; Morley et al., 2013) that is associated with someone's lifestyle (e.g. Brinkman et al., 2018), and socio-economic or

sociodemographic position (e.g. Dury et al., 2016). A second agreement is the acknowledgment of adverse outcomes as a result of frailty, such as mortality, functional decline, hospitalization, and institutionalization (Vermeiren et al., 2016).

Nevertheless, outcomes of being frail should not only focus on adverse or negative consequen-ces. The inclusion of positive frailty outcomes, such as quality of life and/or psychological well-being (e.g., Clegg et al., 2014; Dury et al., 2018; Landi et al., 2017; van der Vorst et al., 2017; Walters et al., 2017), meaning in life and sense of mastery (Dury et al., 2018; van der Vorst et al., 2017) have proven to shed a different perspective on frailty, but were until now rarely studied. Another under researched area is the relationship of environmental factors with frailty (Duppen et al., 2017). Aspects of the social and physical environment, however, are widely recognized as positive influences on the physical and mental health of older adults and their well-being (Annear et al., 2014). There are studies indicating that physical environmental conditions, such as the proximity of green spaces in the neighborhood (Yu et al., 2018) and social environmental factors, like neighborhood cohesion (Cramm & Nieboer, 2013) or participation in social activities (Hoogendijk et al., 2014), are related to frailty or adverse frailty outcomes. Nonetheless, the evidence is still very scarce to draw conclusions for a moderating or mediating effect on frailty (Dent & Hoogendijk, 2015; Duppen et al., 2017).

The importance of the environment is also emphasized by the environmental gerontology theory that addresses the ongoing interchange between the individual and their social and physical environment over the life span (Wahl & Oswald, 2010). Such a person-environment (P-E) fit perspective is relevant in the understanding of the relationship between an individual and his environment and starts from the assumption that a mismatch between personal needs and environmental needs lead to lower behavioral functioning and well-being (Peace, Wahl, Mollenkopf, & Oswald, 2007). Personal needs or the personal dimension in the P-E fit model are explored according to a range of different characteristics specific to aging individuals (Park & Lee, 2017). Examples of the person dimension in recent research include psychological distress (Pai & Kim, 2017), functional limitations, living alone (Kim, Park, Bishop-Saucier, & Amorim, 2017), ethnic background (Riley, Hawkley, & Cagney, 2016) or socioeconomic vulnerabilities (Park & Lee, 2017). Although the environmental dimension in the P-E fit model is most often studied from the

physical/material and the spatial environment (e.g. Granbom, Lofqvist, Horstmann, Haak, & Iwarsson, 2014; Park, Han, Kim, & Dunkle, 2017) environmental gerontology emphasizes the links between the physical and social environment (Peace, Wahl, Mollenkopf, & Oswald, 2007).

P-E fit models also attracted the attention of policy makers. A widely used policy response to population aging is the "aging in place" discourse. Despite the policy strategies for more aging in place for older adults which is also mostly the preference of frail older adults (Wiles, Leibing, Guberman, Reeve, & Allen, 2012), it should be noticed that the living environment can present barriers to active and healthy aging for those who are vulnerable (Annear et al., 2014). In the latest report on aging and health from the WHO, the aging in place concept was extended to aging in the *right* place. This *right* place illustrates a competently P-E fit. A place to age can either be continuing to live in the same home yet also moving to a home that is more adapted to their needs while maintaining vital connections with their community, friends, and family (Beard et al., 2016; World Health Organization [WHO], 2015).

Within the light of aging in the right place, and building on the P-E model, the research at hand investigates the role of both personal (multidimensional frailty) and environmental (physical and social) aspects in their relationship with well-being among frail older adults. Guided by the P-E fit model, the three research questions are:

- Do personal factors (multidimensional frailty) affect well-being in later life (figure 8.1)?
- Do physical and social environmental factors affect well-being in later life (figure 8.1)?
- Do physical and social environmental factors moderate the relationship between frailty and well-being in later life (figure 8.2)?

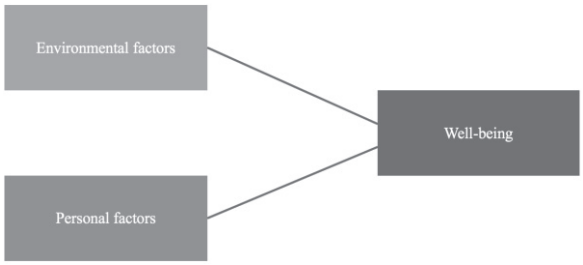


Fig.8.1: conceptual model of independent relationship between P-E factors to well-being

Fig. 8.2: conceptual model of moderating effect environmental factors on personal factors to well-being

3 METHODS

This study used the baseline data of the longitudinal randomized controlled trial of the D-SCOPE project. More information on this study can be found in Lambotte et al. (2018). In sum, the larger D-SCOPE frailty program aimed to detect and to prevent frailty in community-dwelling older adults. In this detection and prevention program, frailty risk profiles were used which are based on age, gender, marital status, migration background, and having moved in the past 10 years (Dury et al., 2016). When frail older adults were

detected, the experimental group was guided towards appropriate care and support. The study was approved by the medical ethics committee of the Vrije Universiteit Brussel, Brussels, Belgium (reference number: B.U.N.143,201,630,458).

Procedure and participants

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 2017. In each municipality, 300 addresses and replacement addresses from residents over 60 years old were randomly selected from the census records. The samples were stratified and based on the aforementioned risk profiles for frailty. Researchers and trained volunteers visited the homes of the older adults who were willing to participate. Given the possible frail situation of the participant, researchers and volunteers assisted the older adults with the questionnaires after the participant signed the informed consent. Exclusion criteria were current hospitalization, institutionalization, when the older adult or his/her informal caregiver indicated participation in the study was impossible or when the interviewer noted that the participant was incapable to provide adequate answers. 869 older adults with a risk profile eventually completed the questionnaire.

Personal factors

As independent variable, the Comprehensive Frailty Assessment Instrument (CFAI-plus) was used to measure 5 dimensions of frailty (De Roeck et al., 2018; De Witte et al., 2013b). The physical domain assesses general physical health (four items, e.g., bending or lifting); the psychological domain evaluates emotional loneliness (three items, e.g. I miss having people around me) and mood-disorders (five items, e.g., unable to cope with problems). The cognitive domain evaluates cognitive functioning (four items, e.g., I have trouble with following a story in a book or on TV). The social domain includes social loneliness (three items, e.g., there are plenty of people I can lean on when I have problems) and social support (three groups of social support networks). The environmental domain was captured by measuring conditions of housing problems (five items, e.g., my house is not comfortable). Each domain of the CFAI-plus represents a subscale which is calculated by adding the scores of the specific items: all subscales ranged from 0 to 100. Subsequently, the scores are accordingly divided by cluster analysis in three natural categories: no to low

frail, mild frail and severe frail. For the present study, all frailty domains were dichotomized (0 = no to low frailty; 1 = mild/sever frailty). The CFAI-plus was previously validated in other studies (De Roeck et al., 2018; De Witte, et al., 2013a; De Witte, et al., 2013b). In the present study, items for four frailty subdomains showed high internal consistency with Cronbach's α reliability scores of 0.822 for physical frailty, 0.849 for psychological frailty, 0.713 for cognitive frailty, 0.719 for social frailty. Environmental frailty had a moderate internal consistency with a 0.656 Cronbach's α score.

Environmental factors

Both the physical as the social environment were tested for having moderating effects on well-being in later life. For all measures, responses were initially given on a 5-point Likert scale ranging from 1 = totally disagree to 5 = totally agree and dichotomized afterwards. If no Dutch version was available for an instrument, a team translation approach called the Translation, Review, Adjudication, Pre-Testing and Documentation (TRAPD) was undertaken to translate the English questions into Dutch.

The *physical environment* was administered by 4 separate items adapted from the questionnaire of the Belgian Aging Studies (BAS) (De Donder et al., 2014) and the Neighbourhood Scale (Cerin, Saelens, Sallis, & Frank, 2006). Respondents were asked if their neighbourhood (a) had sufficient basic services such as a grocery store, bakery and pharmacist; (b) had too much traffic; (c) was accessible by bike or foot; (c) was a safe neighbourhood.

The *social environment* was explored with 2 scales. The first scale measured low-key participation. For this scale, two items from the questionnaire of Oswald and Konopik were used (I know what happens in the neighbourhood, I can talk with my neighbors about the neighbourhood) (Oswald & Konopik, 2015). The questions proved to be internal consistent to use as a scale with a Cronbach's α of 0.706 in the present sample. Three items of the Neighbourhood Scale were used in the evaluation of the social cohesion in the neighbourhood (e.g., people in my neighbourhood usually get along). These items were also reliable as a scale with a Cronbach's α of 0.801.

Well-being measures

Sense of mastery (SOM), meaning in life (MIL) and life satisfaction (LS) were used as dependent variables. SOM was measured with 4 items that measure current mastery, taken from the sense of mastery scale (Pearlin et al., 2007). Based on qualitative interviews prior to this study (Dury et al., 2018), one self-constructed item to assess mastery in relation with others was added: "I can determine how I want things in my life". The total SOM scale in this study was reliable and had a Cronbach's α of .783. MIL was assessed with the Dutch version of the 'presence' subscale of the Meaning in Life Questionnaire (5 items) (Steger et al., 2006). Reliability for these items was Cronbach's α of .877. LS was measured with the Satisfaction with Life Scale (5 items) (Diener et al., 1985). Reliability for the last scale in this study was also good with a Cronbach's α of .815.

Control variables

Several variables were included in the analyses to account for the characteristics of the respondents. Sociodemographic characteristics were age, gender (1 = male; 2 = female) and partnership (0 = no partner; 1 = partner). Socioeconomic characteristics included monthly household income (1 = <€1000; 2 = between €1000 and €1250; 3 = €1251 and €1499; 4 = between €1500 and €1999; 5 = between €2000 and €2500; 6 = >€2500) and education (1 = no completed education; 2 = primary education; 3 = lower secondary education; 4 = higher secondary education; 5 = higher education).

Statistical analysis

In the first step, descriptive statistics were calculated to report an overview of the characteristics between the frail and non-frail participants for each domain. Differences between groups were established using χ^2-tests, Mann-Whitney test and t-tests. In the second step, general linear models (GLM) were performed to determine the main effect of each domain of frailty separately (i.e. physical, psychological, cognitive, social and environmental frailty) and environmental factors on the well-being outcomes sense of mastery, meaning in life, and life satisfaction. We controlled for age, gender, monthly household income, and education. In the final step, a second set of GLM was carried out to find an interaction effect between the multidimensional frailty and environmental factors on well-being. The results of these analyses are reported in beta values and

significance within the models were reached when $p < .05$. All statistical analyses were performed with the software SPSS version 25.

4 Results

Table 8.1 presents the characteristics of the participants. Mean age was 75.24 years and 49.4% of the sample were women. 61.4% of the older adults had no partner. A minority had a household income of less than €1000 and primary education only (6.1%) or less (1.9%). Less than half of the respondents reported high levels of the physical environment. Social environmental factors scored higher. Scores on the well-being scales tended to be high.

In the multivariate analysis, first, GLM were carried out to find independently the relationship between either the personal factors (frailty) and the environmental factors (physical and social environment) to the well-being outcomes sense of mastery, meaning in life and life satisfaction. Second, additional GLM were completed to examine the interaction effects of the environment between frailty and well-being outcomes. All results were controlled for the covariates age, gender, partnership, monthly household income and education. Table 8.2 presents the independent relationship between personal and environmental factors to well-being. In terms of personal factors, all domains of frailty, were associated with a lower sense of mastery, meaning in life and life satisfaction.

Regarding the physical environment, the presence of basic services in the neighbourhood, high accessibility and feeling safe in the neighbourhood were associated with higher sense of mastery, meaning in life and life satisfaction. Low traffic in the neighbourhood was only associated with higher sense of mastery. The association of low traffic with meaning in life and life satisfaction was not significant. For the social environment, both social cohesion and low-key participation were associated with the well-being outcomes.

Table 8.1: Participant characteristics

	Mean *(SD)* or %
demographics	
age	75,24 (8,04)
women	49,4
no partner	61,4
household income	
<€1000	4,6
€1000 - €1250	22,8
€1251 - €1499	20,5
€1500 - €1999	21,4
€2000 – €2500	15,2
>2500	15,5
education	
no completed education	1,9
primary education	6,1
lower secondary education	29,8
higher secondary education	37,1
higher education	25,1
physical environment	
plenty basic services	46,6
low traffic	28,4
highly accessible	48,4
safe neighbourhood	40,9
social environment	
social cohesion (3-15)	11,44 (2,82)
low-key particip. (2-10)	6,60 (2,37)
outcomes	
sense of mastery (5-25)	20,15 (4,58)
meaning in life (5-25)	20,32 (4,37)
Life satisfaction (5-25)	18,90 (4,42)

Table 8.3 presents the moderation analysis of between all personal factors and environmental factors. 9 interaction effects were found. The presence of many basic services negatively moderated the relationship between psychological frailty and sense of mastery (b = -1.657, 95% CI [-2.854, -0.460], t = -2.719, p = 0.007), meaning in life (b = -1.377, 95% CI [-2.660, -0.095], t = -2.108, p = 0.035) and life satisfaction (b = -2.216, 95% CI [-3.417, -1.015], t = -3.622, p = 0.000). Older adults who were not psychologically frail scored had higher levels of sense of mastery, meaning in life and life satisfaction when they had many basic services in the neighbourhood.

Table 8.2: GLM regression personal factors (frailty domains) and environmental factors on well-being

	Sense of mastery	Meaning in life	Life satisfaction
personal factors			
physical frailty *B*	-3.223*	-1.734*	-2.058*
psychological frailty *B*	-4.632*	-3.088*	-3.468*
cognitive frailty *B*	-3.021*	-1.991*	-1.754*
social frailty *B*	-2.308*	-2.688*	-2.081*
environmental frailty *B*	-2.392*	-1.534*	-1.485*
environmental factors			
physical environment			
basic services *B*	1.197*	0.887*	1.240*
traffic *B*	0.800*	0.582	0.647
accessibility *B*	2.943*	2.210*	2.294*
safety *B*	1.551*	1.607*	1.774*
social environment			
social cohesion *B*	0.434*	0.367*	0.440*
low-key participation *B*	0.378*	0.463*	0.506*

Note: all displayed values = p < 0,05; *B* = unstandardized regression coefficients; all models controlled for age, gender, partnership, monthly household income and education

However, for older adults in the psychological frail group, the presence of many basic services was associated with lower levels for sense of mastery, meaning in life and life

satisfaction these outcomes and less basic services in the neighbourhood was associated with higher levels for these outcomes (Figure 8.3, panels a, b and c). More negative coefficients of the moderator basic services were found between physical frailty and life satisfaction (b = -1.286, 95% CI [-2.492, -0.081], t = -2.095, p = 0.037) and between cognitive frailty and life satisfaction (b = -1.527, 95% CI [-2.728, -0.326], t = -2.497, p = 0.013). Here, the levels of life satisfaction significantly decreased for the frail group. The physical and cognitive frail group however remained a higher level of life satisfaction when there were basic services present (Figure 3, panels d and e). A last negative interaction affect was found for feelings of safety in the neighbourhood. A safe neighbourhood negatively moderated the relation between psychological frailty and meaning in life (b = -1.975, 95% CI [-3.272, -0.679], t = -2.992, p = 0.003). Older adults who were not psychologically frail who felt highly safe in the neighbourhood had higher levels of meaning in life than those who felt less safe. The opposite was found for the frail group who had lower levels of meaning in life when they felt highly safe compared to those who felt less safe (Figure 8.3, panel f).

Figure 8.3, panel g, shows there was no significant difference in the level of meaning in life between high or low traffic for older adults who were not psychologically frail. However, low traffic in the neighbourhood positively moderated the relationship between meaning in life and psychological frailty (b = 1.478, 95% CI [0.056, 2.900], t = 2.041, p = 0.042).

Last positive interactions were found for low-key participation between meaning in life and psychological frailty (b = 0.334, 95% CI [0.055, 0.612], t = -2.353, p = 0.019) and life satisfaction and environmental frailty (b = 0.271, 95% CI [0.015, 0.526], t = 2.082, p = 0.038). No plots for the latter two interactions are displayed due to the scale characteristic of the variable.

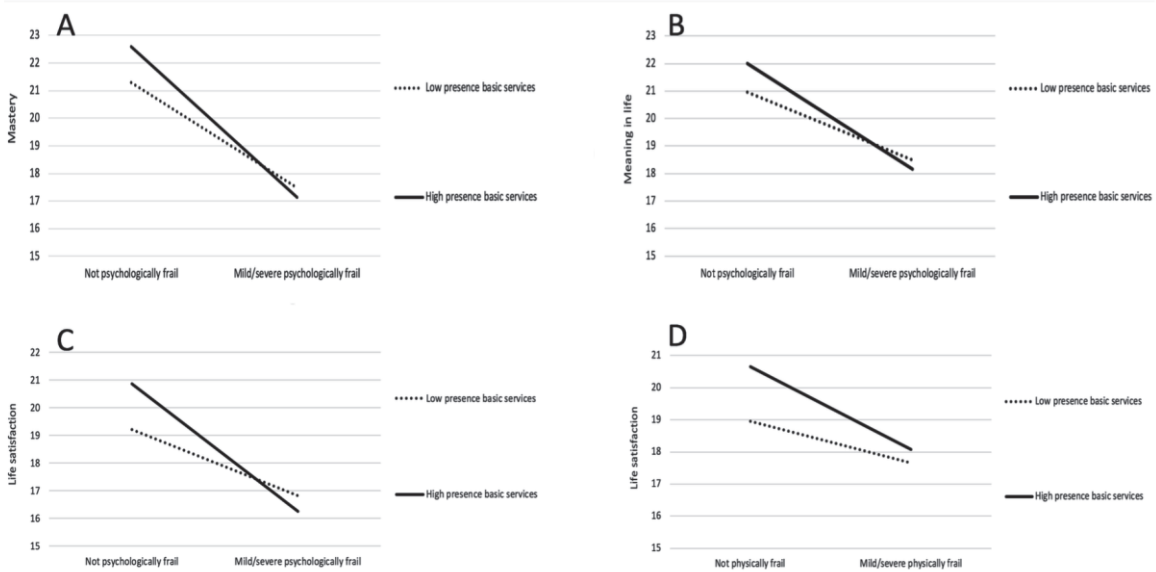
All other regression coefficients were not significant. In these situations, outcomes for well-being were higher for both the non-frail and the mild/severe frail group when the environment was more desirable. Figure 3, panel i, illustrates these situations by example of neighborhood accessibility and physical frailty to sense of mastery.

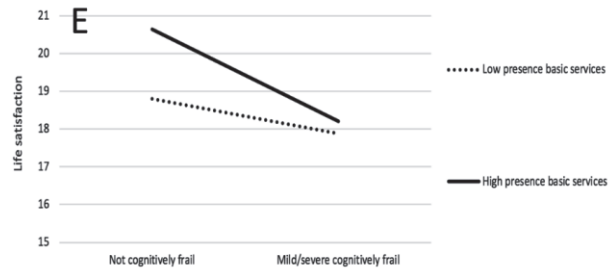
Table 8.3: GLM regression with environmental factors and personal factors (CFAI-plus domains no vs. mild/severe frail)

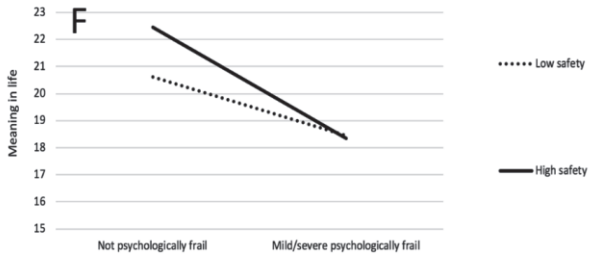
	Sense of Mastery					Meaning in Life					Life Satisfaction				
	Phy.	Psy.	Cog.	Soc.	Env.	Phy.	Psy.	Cog.	Soc.	Env.	Phy.	Psy.	Cog.	Soc.	Env.
physical environment															
basic services															
ME CFAI-plus *B*	-3.156*	-4.512*	-2.899*	-2.210*	-2.279*	-1.641*	-3.032*	-1.938*	-2.617*	-1.426*	-1.937*	-3.350*	-1.653*	-1.983*	-1.313*
ME basic services *B*	0.866*	0.690*	0.945*	1.086*	0.791*	0.711*	0.550	0.611	0.746*	0.658*	1.039*	0.858*	1.079*	1.128*	0.966*
Interaction *B*	-0.559	-1.657*	0.066	-1.013	-0.217	-0.875	-1.377*	-0.492	-1.193	-0.029	-1.286*	-2.216*	-1.527*	-0.216	-0.792
traffic															
ME CFAI-plus *B*	-3.199*	-4.626*	-2.998*	-2.301*	-2.347*	-1.743*	-3.103*	-1.925*	-2.669*	-1.504*	-2.050*	-3.500*	-1.728*	-2.071*	-1.442*
ME traffic *B*	0,646	0.520	0.592	0.801*	0.271	0.466	0.247	0.467	0.550	0.330	0.569	0.322	0.549	0.630	0.309
Interaction *B*	0,506	-0.750	-0.324	1.256	1.067	-0.123	-1.326	-1.208	0.534	1.478*	0.600	-1.132	-0.834	0.543	0.434
accessibility															
ME CFAI-plus *B*	-2.561*	-4.054*	-2.570*	-1.698*	-1.822*	-1.160*	-2.628*	-1.638*	-2.279*	-1.088*	-1.432*	-3.038*	-1.402*	-1.676*	-1.062*
ME accessibility *B*	2.221*	1.996*	2.475*	2.567*	2.498*	1.896*	1.507*	1.872*	1.725*	2.022*	1.981*	1.499*	2.017*	1.927*	2.033*
Interaction *B*	0.206	0.151	0.504	0.653	0.551	-0.427	0.558	-0.309	-0.111	0.273	-0.213	-0.663	-0.695	0.746	0.122
safety															
ME CFAI-plus *B*	-3.064*	-4.470*	-2.899*	-2.037*	-2.135*	-1.539*	-2.892*	-1.841*	-2.442*	-1.218*	-1.834*	-3.241*	-1.584*	-1.753*	-1.091*
ME safety *B*	1.193*	0.983*	1.254*	1.176*	1.010*	1.467*	1.187*	1.398*	1.083*	1.333*	1.624*	1.305*	1.598*	1.373*	1.451*
Interaction *B*	0.499	-0.178	0.523	-0.158	0.107	-0.688	-1.975*	-0.267	-0.744	-0.569	-0.513	-0.449	0.538	0.048	-0.858
social environment															
social cohesion															
ME CFAI-plus *B*	-2.828*	-4.258*	-2.841*	-1.715*	-1.820*	-1.461*	-2.636*	-1.740*	-2.255*	-1.044*	-1.619*	-2.952*	-1.490*	-1.513*	-0.862*
ME social cohesion *B*	0.356*	0.230*	0.359*	0.359*	0.358*	0.333*	0.247*	0.331*	0.254*	0.332*	0.400*	0.312*	0.405*	0.357*	0.398*
Interaction *B*	-0.074	0.064	-0.086	-0.004	-0.028	-0.132	0.182	-0.162	0.144	-0.081	0.010	0.204	-0.094	-0.036	-0.115
low-key participation															
ME CFAI-plus *B*	-3.004*	-4.552*	-2.872*	-2.113*	-2.162*	-1.480*	-2.851*	-1.754*	-2.446*	-1.255*	-1.718*	-3.189*	-1.519*	-1.680*	-1.257*
ME low-key participation *B*	0.284*	0.207*	0.303*	0.295*	0.324*	0.416*	0.354*	0.423*	0.353*	0.454*	0.458*	0.398*	0.467*	0.429*	0.491*
Interaction *B*	-0.129	0.160	-0.210	0.037	0.159	-0.087	0.344*	-0.088	0.159	-0.014	0.012	0.122	-0.015	0.077	0.271*

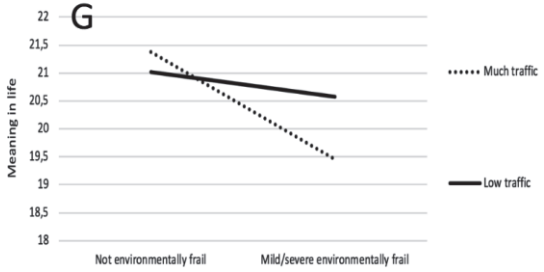
Note: * = p < 0,05; Phy. = Physical frailty; Psy. = Psychological frailty; Cog. = Cognitive frailty; Soc. = Social frailty; Env. = Environmental frailty; ME = main effect. All models controlled for age, gender, partnership, monthly household income and education, *B* = unstandardized regression coefficients

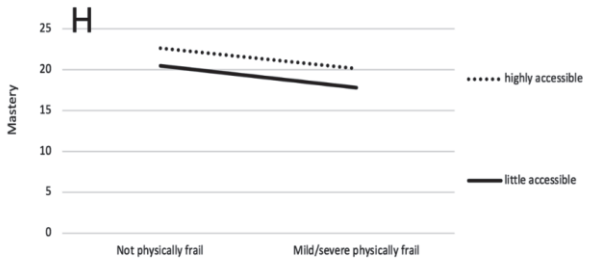
Fig. 8.3: Changes in levels of well-being according to physical environmental factors.











5 Discussion

This study researched whether frailty in later life and environmental factors were related to well-being and whether environmental factors moderated the relationship between frailty and well-being. By means of a Person-Environment fit model, this study builds further on environmental gerontology theory. The study uses several novel approaches. First, opposed to the most commonly physical approach of frailty, five different dimensions of frailty were included. Next to physical frailty, also a psychological, cognitive, social and environmental frailty were included as personal factors within the P-E fit model. Second, for the environmental factors, both the physical and the social environment were included in the model. Third, the inclusion of multiple domains of well-being as a frailty outcome is only used recently in frailty research (Dury et al., 2018; van der Vorst et al., 2017). The results in this study indicate that all dimensions of frailty were related with a lower sense of mastery, meaning in life and life satisfaction.

Earlier research demonstrated the relevant role of the physical environment (Park & Lee, 2017; Xie, 2018) and the social environment (Park & Lee, 2017) on older adults' life satisfaction. Our findings show that in addition to life satisfaction, higher levels for sense of mastery and meaning in life were found when older adults lived in a better physical and social environment. The only exception was when neighborhoods did not have too much traffic, which was only associated with more sense of mastery. Looking at the interaction effects, in most situations, environmental factors did not interact in the relation between frailty and well-being. Only three positive interactions were found. Low-key participation moderated the relationship between psychological frailty and meaning in life and between environmental frailty and life satisfaction. Low traffic in the neighbourhood in its turn showed higher levels of meaning in life for environmental frail older adults. Negative interactions were found for the presence of basic services and all dimensions of well-being for psychologically frail older adults and with life satisfaction for cognitively and physically frail older adults.

As for the relation between well-being and frailty, levels of well-being were lower for the frail groups compared to the non-frail group. Nonetheless, the level of well-being remained

higher in both the frail as the non-frail group when residing in a better social and physical environment.

These findings have several implications for age-friendly environmental reasoning. First, in many cities and communities, age-friendly strategies are implemented to enable aging in place (e.g., Lin & Huang, 2016; Schorr & Khalaila, 2018). In the debate whether age-friendly strategies should primarily target healthy older adults rather than those who are frail (Golant, 2014), the findings of this study argue that in general both groups benefit from an age-friendly environment. This argument is supported by the findings of an earlier study discussing that age-friendly environments are especially important for frail older adults (Cramm, van Dijk, & Nieboer, 2018). Second, age friendly initiatives reflect the strength of community support in the feasibility to age in place instead of focusing on the individual (Greenfield, Oberlink, Scharlach, Neal, & Stafford, 2015). Apart from benefits of an age-friendly environment, individual support is still strongly needed given the fact that the levels of well-being for psychologically frail older adults in this study were lower in an age-friendly environment than for non-frail psychologically frail older adults. Third, current academic focus on the relationship between the environment and well-being is mainly concerned with housing quality or the home environment (Herbers & Mulder, 2017; Oswald et al., 2007). Age-friendly policy strategies, as well as P-E fit research should include also the social and the physical living environment.

There are several limitations to this study. A first shortcoming is the preventive nature of the overall D-SCOPE project in assessing frailty in later life, meaning that the study population entails non-frail, mild and severe frail older people. Being socially or psychologically frail, for example, indicates that these older adults experience a lack in social support, feel lonely or experience distress. Future research should consider researching P-E relations in an even more vulnerable older population. Since we found negative interactions in the psychologically frail group, future research should focus on those who experience severe loneliness or depressive symptoms. Second, there are more factors that shape the physical and social environment which were not included in this research. From an age-friendly perspective, other age friendly domains such as civic participation, social inclusion and use of public transport are worth exploring in further

research. Third, the environmental measures in this research are perceived by older adults themselves. The vicinity of basic services in the neighbourhood, for example, is very subjective. Objective neighbourhood characteristics such as neighbourhood socioeconomic deprivation have a relationship with frailty in later life (Lang, Llewellyn, Langa, Wallace, & Melzer, 2008). Comparable data however, was not available for this research. Fourth, despite this study used validated scales to assess all frailty domains and well-being measures, it should be noted that there is a potential overlap between one item of the psychological domain of the CFAI-plus (i.e. I feel like I cannot cope with problems, De Roeck et al., 2018) and the Sense of Mastery scale (i.e. I can't solve some of the problems I have, Pearlin et al., 2017). Although there is a difference between coping with problems and problem solving, a contamination between both constructs is present (Boateng, Neilands, Frongillo, Melgar-Quiñonez, & Young, 2018). A last limitation is that all participants lived in a densely populated urbanised region. Environmental characteristics such as accessibility and social cohesion differ between rural and urban areas (van den Berg, Sharmeen, & Weijs-Perree, 2017). The findings of this study cannot be generalized to rural areas or large metropolitan cities.

6 Conclusion

This cross-sectional study indicates that frail older adults have lower levels of well-being than older adults who are not frail. Physical and social environmental factors have a positive relationship with well-being in later life. In general, these environmental factors, however, do not positively moderate the relationship between frailty and well-being. Overall, older adults, frail or not frail, benefit from a better physical and social environment.

7 References

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Chapter 9

Exploring the Possibility of Antenna Professions in the Detection of Frail Community Dwelling Older Adults

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1 Samenvatting

Zowel in Vlaanderen als in Nederland werd de voorbije jaren sterk geïnvesteerd in preventie en interventieprogramma's om kwetsbaarheid bij ouderen tegen te gaan. Kwetsbaarheid wordt doorgaans gedetecteerd door gezondheidsprofessionals. Deze studie exploreerde hoe andere professionals buiten de zorgsector zoals postbodes, winkelbediendes of apothekers een antennefunctie kunnen hebben in de detectie van kwetsbare ouderen door hen door te verwijzen naar zorg wanneer dit nodig is. Daarnaast werd nagegaan in welke situaties zij acties ondernemen en welke ondersteuning nodig is om de rol van antenneberoep op te nemen. 18 professionals werden geïnterviewd. Resultaten van de kwalitatieve analyse tonen aan dat zij veelvuldig in contact komen met kwetsbare ouderen tijdens het uitoefenen van hun beroepsactiviteit. Door in gesprek te gaan met de ouderen detecteren zij verschillende vormen van kwetsbaarheid. Zij kunnen en willen een sleutelrol opnemen om deze ouderen door te verwijzen naar zorgondersteuning maar stellen zich vragen omtrent de privacy. Een centraal meldpunt per gemeente zien zij als een oplossing.

Trefwoorden: ouderen – oudere volwassenen – kwetsbaarheid – detective - preventie

2 Inleiding

De maatschappij waar we in leven ontgroent en vergrijst. 16,3% van de Belgische bevolking was in 2016 ouder dan 67 jaar ten opzichte van 14,7% in 2000 en verwacht wordt dat dit percentage oploopt tot 22,1% in 2040 (Federaal planbureau, 2017). De Belgische situatie is overeenkomstig met andere Europese landen. Zo wordt er geschat dat over heel Europa (EU-28) 27% van de bevolking in 2040 65 jaar of ouder zal zijn (Eurostat, 2018). Deze bevolkingsvooruitzichten zorgen voor een demografische shift en ze hebben implicaties op en opportuniteiten voor iedereen in onze samenleving. Enerzijds nemen ouderen tot op hoge leeftijd verschillende rollen op: vb. in de zorg voor familie en naasten, via vrijwilligerswerk of in het verenigingsleven. Zolang ouderen gezond zijn, worden zij in het uitvoeren van deze activiteiten amper beperkt (Wereldgezondheids-organisatie, 2015). Bij toenemende kwetsbaarheid echter daalt de maatschappelijke participatie van ouderen. Wat deze kwetsbaarheid inhoudt, wordt in de wetenschappelijke

literatuur benaderd vanuit twee invalshoeken. Enerzijds is er de focus op hoofdzakelijk biomedische en fysieke kwetsbaarheid waarbij gekeken wordt naar een optelsom van fysieke symptomen of aandoeningen zoals spontaan gewichtsverlies of vertraagde wandelsnelheid (vb. Fried e.a., 2001, Rockwood, Mitnitski, Song, Steen, & Skoog, 2006). Anderzijds is er de holistische benadering waarbij kwetsbaarheid niet als een statisch maar een dynamisch gegeven bekeken wordt dat doorheen de tijd positief of negatief kan evolueren. Kwetsbaarheid manifesteert zich hier op meer domeinen dan enkel lichamelijke gezondheid (Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010). In de meest uitgebreide operationalisering van kwetsbaarheid worde naast fysieke kwetsbaarheid nog vier andere domeinen voorgesteld. Een tweede domein is psychische kwetsbaarheid die rekening houdt met emotionele eenzaamheid en stemmingsstoornissen. Een derde domein omvat sociale kwetsbaarheid en includeert zowel sociale eenzaamheidsgevoelens als het ontbreken van een steunnetwerk. Cognitieve kwetsbaarheid houdt rekening met geheugenproblemen en omgevingskwetsbaarheid gaat onder meer over een niet-aangepaste woonomgeving (Dury e.a., 2018; van der Vorst e.a., 2017).

2.1 Naar een tijdige detectie van kwetsbaarheid

Onderzoek toont aan dat een vroegtijdige tussenkomst bij symptomen van kwetsbaarheid een ziekenhuis- of rusthuisopname mogelijks kan uitstellen of vermijden (Stijnen, Duimel-Peeters, Jansen, & Vrijhoef, 2013). Vandaag de dag gebeurt detectie van kwetsbaarheid voornamelijk in een medische setting, zoals in een ziekenhuis, bij de huisarts (Lette, Baan, van den Berg, & de Bruin, 2015) of door proactieve huisbezoeken door verpleegkundigen (Hout e.a., 2011). Deze zorgprofessionals zijn als het ware de sleutelfiguren om kwetsbaarheid te detecteren. Ouderen die echter geen gebruik maken van professionele (medische) zorg moeten bij problemen een beroep doen op hun eigen inschattings-vermogen of hun eigen informeel netwerk (Fabbricotti e.a., 2013; Jonkers & Machielse, 2012). Helaas zijn er ouderen met een zeer klein sociaal netwerk. Extreme voorbeelden van sociale isolatie die de media halen, zijn de overlijdens van ouderen waarbij het lichaam pas maanden of jaren na hun overlijden werd gevonden. Zo werden in de zomer van 2017 in de stad Brugge op één week tijd drie lichamen gevonden van personen die reeds enkele dagen overleden waren (bron standaard 2 augustus 2017). Dit gaf de aanleiding om in de stad het actieplan ‘vierkant tegen eenzaamheid’ op te starten met acties zoals een

telefoonketting of *alerte deurprofessionals*. Deze professionals komen vanwege hun beroep voorbij de deur van inwoners en zouden de detectie naar eenzaamheid en isolement bij ouderen kunnen ondersteunen (Vierkant tegen eenzaamheid, 2018).

2.2 Preventie van kwetsbaarheid: rol van antenneberoepen.

Om extreme situaties tegen te gaan, is er reeds bij de eerste symptomen van kwetsbaarheid nood aan een interventie om de situatie aan te pakken (Lette, e.a., 2015; Stijnen, e.a., 2013). Zowel in Vlaanderen als in Nederland werd er de voorbije jaren ernstig geïnvesteerd in preventie en interventie-programma's voor kwetsbare ouderen. Een voorbeeld uit Nederland is het *Even Buurten* project in Rotterdam waar sociale netwerken van thuiswonende ouderen via een integrale wijkaanpak worden versterkt om zo kwetsbaarheid vroeger te signaleren (van Dijk, Cramm, Lötters & Nieboer, 2013). Een voorbeeld uit Vlaanderen is dat van *Actief Zorgzame Buurten*. In dergelijke buurten kennen en helpen bewoners elkaar, wordt zorg breed bekeken en wordt er ondermeer gebouwd aan sociale cohesie in de wijk (De Donder e.a., 2017).

Van 2015 tot einde 2018 loopt in Vlaanderen het Detection – Support and Care for Older People: Prevention and Empowerment project (D-SCOPE) waarin een methodiek ontwikkeld werd om ouderen met een verhoogd risico voor kwetsbaarheid te detecteren aan de hand van gegevens uit het bevolkingsregister (Lambotte e.a., 2018; Smetcoren e.a., 2017). Daarnaast wil D-SCOPE exploreren hoe 'niet-evidente' professionals kwetsbaarheid kunnen detecteren en signaleren wanneer zij vanuit hun beroep in contact komen met kwetsbare ouderen. Zoals een antenne verschillende radiogolven ontvangt, zijn er ook antenneberoepen (AB) die verschillende signalen van hun klanten en cliënten ontvangen betreft kwetsbaarheid en eventuele zorgtekorten. We denken hierbij aan apothekers, kappers/kapsters, loketbedienden van een financiële instelling, cafébazen, winkelbedienden/ kassiers(ters), postbodes en veel meer. Aan de hand van een exploratieve studie wil D-SCOPE nagaan:

1. Kunnen antenneberoepen kwetsbaarheid bij thuiswonende ouderen detecteren? En hoe doen zij dit?

2. In welke situatie zij actie ondernemen als ze kwetsbaarheid bij thuiswonende ouderen met een zorgtekort detecteren en welke knelpunten zij hierbij ervaren?
3. Welke ondersteuning belangrijk is om de rol van antenneberoep op te nemen?

3 METHODE VAN ONDERZOEK

Van januari 2015 tot december 2018 werken 21 onderzoekers van de Vrije Universiteit Brussel, Universiteit Antwerpen, Katholieke Universiteit Leuven, Hogeschool Gent en Maastricht University samen aan het D-SCOPE-project. D-SCOPE ontwikkelde gedurende deze periode strategieën voor een proactieve detectie van kwetsbaarheid bij thuiswonende ouderen (60 jaar en ouder). Naast de detectie van kwetsbare ouderen via het bevolkingsregister aan de hand van risicoprofielen (Smetcoren et al., 2017) werd verkend hoe antenneberoepen kwetsbare ouderen konden signaleren en doorverwijzen naar het Openbaar Centrum voor Maatschappelijk Welzijn (OCMW) die dan de gepaste en gewenste hulp zou kunnen inschakelen.

Data werden verzameld door interviews met personen in antenneberoepen. Hoewel de originele opzet focusgroepen waren, werden wegens praktische omstandigheden zoals, druk werkschema, overlappende uurregelingen, annulatie wegens permanentie of het niet verkrijgen van dienstvrijstelling ook aanvullend individuele interviews georganiseerd om zo divers mogelijke respondenten te kunen bereiken. Een onderzoeker van D-SCOPE coördineerde de gesprekken in de 2 focusgroepen (n=2; n=4) en werd daarin bijgestaan door een masterstudent Agogische Wetenschappen en een medewerker van het OCMW. De onderzoeker en de student namen aanvullend nog 10 individuele interviews en één dubbelinterview met personen in antenneberoepen af tot datasaturatie optrad.

3.1 Onderzoekspopulatie en onderzoeksobject

In totaal werden 18 personen met verschillende beroepen geïnterviewd: apothekers (n=3), bedienden (n=2), handelaars (n=6), andere zelfstandigen (n=4) en dienstverleners (n=3). Volledige karakteristieken van de deelnemers zijn terug te vinden in tabel 9.1. De deelnemers werden benaderd via de medewerkers van het OCMW of via contacten uit de

netwerken van D-SCOPE-onderzoekers. Enkel professionals die via hun beroep in contact kwamen met kwetsbare thuiswonende ouderen werden geïncludeerd in het onderzoek. Exclusiecriteria waren professionals zonder thuiswonend ouder cliënteel of professionals die een zorgberoep uitoefenden zoals huisartsen, thuiszorgdiensten, thuisverpleegkundigen, of kinesitherapeuten en reeds een gekende sleutelrol in detectie hebben.

Tabel 9.1: karakteristieken van de deelnemers

Beroep	Leeftijd	Positie	Geslacht
Vrij beroep			
Apotheek grootstad	30	Hoofdapotheker	Man
Apotheek stad	31	Hoofdapotheker	Vrouw
Apotheek dorp		Hoofdapotheker	Man
Bediende			
Café	32	Serveuse	Vrouw
Buurtwinkel [c]	51	Kassierster	Vrouw
Handelaar			
Fruitwinkel [a]	64	Zaakvoerder	Man
Dagbladhandel [a]	50	Eigenaar	Vrouw
Bakker	61	Zaakvoerder	Man
Bloemenwinkel	61	Zaakvoerder	Man
Buurtwinkel [c]	47	Zaakvoerder	Vrouw
Grootwarenhuis [b]	46	Manager	Man
Andere zelfstandige			
Schoonheidsspecialiste [a]	29	Zelfstandige	Vrouw
Kapsalon	68	Zelfstandige	Vrouw
Kapster aan huis	47	Zelfstandige	Vrouw
Bankkantoor	54	Filiaalhouder	Man
Dienstverlening			
Bpost	53	Postbode	Vrouw
Bpost [a]	39	Postbode	Man
Lokale politie [b]	53	Inspecteur wijkagent	Vrouw

[a] = deelnemers focusgroep Tienen; [b] = deelnemers focusgroep Knokke-Heist; [c] = duo interview

Gezien de exploratieve aard van het onderzoek werd gekozen voor kwalitatieve interviews om de ervaringen en noden van AB te onderzoeken. Hierbij waren 4 hoofdvragen centraal: (a) “In welke situaties komt u in contact met kwetsbare ouderen van wie u denkt dat ze extra hulp of zorg zouden nodig hebben?”; (b) “In welke situatie hebben jullie al eens kwetsbare ouderen gedetecteerd en die effectief ook doorverwezen naar meer zorg en

ondersteuning?"; (c) "Hoe vult u de rol van AB in en welke ondersteuning heeft u hiervoor nodig?"; (d) Welke mogelijke drempels kan iemand ondervinden om de rol als AB op te nemen?" Elk interview werd digitaal opgenomen en later verbatim getranscribeerd. Elke deelnemer ondertekende geïnformeerde toestemming voor deelname, opname van het gesprek en een vertrouwelijke verwerking van de data voor wetenschappelijke doelen. De studie werd goedgekeurd door de ethische commissie van de Humane Wetenschappen van de Vrije Universiteit Brussel (ECHW_031).

3.2 Wijze van analyseren

Met behulp van de software MAXQDA werden de kwalitatieve interviews geanalyseerd volgens thematische analyse. In een eerste stap werden vier hoofdthema's bepaald: (a) gedetecteerde vormen van kwetsbaarheid; (b) ondernomen acties; (c) knelpunten naar doorverwijzing; (d) noden voor doorverwijzing. In een tweede stap werden alle interviews geanalyseerd en leidde inductieve analyse ertoe dat subthema's werden toegekend aan nieuwe informatie die naar boven kwam onder de hoofdthema's (Fereday & Muir-Cochrane, 2006). Eén onderzoeker deed alle analyses waarna deze werden bediscussieerd met alle onderzoekers van deze studie. Elk hoofdthema werd uitvoerig beschreven met informatie uit de subthema's en geïllustreerd met citaten van de deelnemers in het onderzoek om de essentie van het thema duidelijk te maken (Crowe, Inder, & Porter, 2015). Om de anonimiteit van de deelnemers te garanderen werden schuilnamen gebruikt.

4 Resultaten

4.1 Detecteren van kwetsbare ouderen

Professionals met een antenneberoep detecteren kwetsbare ouderen op verschillende manieren. AB nemen vage alarmsignalen van *cognitieve kwetsbaarheid* waar of hebben een 'niet pluis gevoel'. Voorbeelden waar ze mee geconfronteerd worden, zijn: het vergeten ophalen van medicatie in de apotheek, vergeten waar belangrijke financiële documenten zijn, een verhaal vaak herhalen, pincode vergeten of hetzelfde magazine als de dag voorheen kopen in de dagbladhandel. In een café merkt de serveerster op dat ouderen met geheugenproblemen hun portemonnee geven en vragen om het geld er zelf uit te

nemen. *Fysieke kwetsbaarheid* is volgens de respondenten visueel herkenbaar wanneer ouderen hulpmiddelen beginnen te gebruiken zoals een rollator of wanneer boodschappen te zwaar worden. In zeldzame gevallen merken zij urinaire incontinentie op of flauwte door hypoglykemie bij diabetespatiënten. *Sociale kwetsbaarheid* toont zich wanneer eenzame oudere mannen de kassiersters vragen om mee uit te gaan of wanneer ouderen vaak in de winkel blijven 'hangen'. Een ander voorbeeld van sociale kwetsbaarheid is het gebruik maken van de thuislevering service van de buurtwinkel door ouderen die fysiek kwetsbaar zijn, maar waarbij de sociale kwetsbaarheid duidelijk wordt door elke dag voor één levering te bellen in plaats van éénmaal per week om toch maar iemand te zien. Ook een postbode merkt op dat hij voor bepaalde ouderen de enige is die bij hen langskomt. *Omgevingskwetsbaarheid* wordt door AB eerder gezien als een niet-verzorgde woning (vb. gebrek aan hygiëne) dan een woning die niet is aangepast aan de leeftijd. Dit wordt ook enkel gedetecteerd door AB die aan huis komen zoals kapster, postbode, bankfiliaalhouder of schoonheidsspecialist. *Psychische kwetsbaarheid* is zichtbaar wanneer ouderen 'een traantje wegpinken' bij verhalen over hun overleden partner. Wanneer AB vertellen over complexe zorgsituaties komen *verschillende vormen van kwetsbaarheid* naar boven. Voorbeelden zijn cognitieve problemen bij ouderen met een beperkt sociaal netwerk waarbij een evolutie zichtbaar is naar meer verwaarlozing. In specifieke situaties krijgen de AB te maken met psychiatrische stoornissen, alcoholmisbruik en verwaarlozing. In een landelijke buurtwinkel werden AB hier ongevraagd mee geconfronteerd zoals blijkt uit volgend dubbelinterview:

> *Helène: "Ja. Je hebt Frank, die aan de drank zit. Op een bepaald moment, je ziet hem achteruitgaan."*
> *Eliane: "Dat zijn mensen, die dan zeggen: 'Kijk, Helène en Eliane, ik ga me laten opnemen.' Die komt dat dus vertellen, ondanks dat wij die mens eigenlijk gewoon niet kennen. Alleen van in de winkel. Maar gewoon, die komt zeggen: 'Ik laat me opnemen. Ik ga veertien dagen weg zijn.' En die komt dat vertellen. Hij moet ook zijn ei kwijt kunnen. Dat is ook een meneer alleen. Alleen gevallen (verweduwd)."*

Naast de gekende vormen van kwetsbaarheid wordt ook financiële kwetsbaarheid aangehaald. AB vertellen dat ze vaak op de hoogte zijn dat bepaalde klanten onder budgetbeheer staan. Anderen zoals de schoonheidsspecialiste en kapster, ervaren dat ouderen vanwege financiële redenen minder afspraken maken dan ze zouden wensen.

4.2 Acties ondernemen en knelpunten om tot actie over te gaan

Elke respondent geeft aan in het verleden reeds één of meerdere acties te hebben ondernomen om zijn kwetsbaar ouder publiek te ondersteunen. Voor bepaalde AB is actie ondernemen verbonden aan hun beroep. De bankfiliaalhouder *adviseert* bijvoorbeeld zijn ouder cliënteel vaak om een zorgvolmacht op te maken in geval de oudere door ziekte of ongeval wilsonbekwaam wordt. In dergelijk geval kan de persoon met de volmacht alle bankzaken regelen voor de wilsonbekwame oudere. Apothekers gaven aan dat advies geven over medicatie en zorg tot hun functie behoort. Het *leveren aan huis van levensmiddelen* aan kwetsbare ouderen is bij de landelijke buurtwinkel een standaard service, terwijl dit bij de fruitkweker een uitzonderlijke mogelijkheid is. Het grootwarenhuis biedt deze service aan bij een aankoopbedrag van minimum € 75. Voorbeelden van extra's die tot heden door AB worden aangeboden zijn het installeren van een koffiecorner of zitbank in de lokale winkel. Eén postbode geeft aan dat hij na zijn uren voor ouderen naar de apotheker rijdt. *Luisteren naar het verhaal van de oudere* wordt eveneens benadrukt als het bieden van hulp. Dit was volgens de serveerster enkel mogelijk tijdens rustige momenten, wanneer er geen andere klanten in het café zijn. AB werken op bepaalde vlakken ook *preventief:* Een apotheker vraagt bijvoorbeeld aan ouderen of zij op iemand kunnen rekenen in geval van nood en trachten een vertrouwensrelatie op te bouwen met psychiatrisch zieke ouderen. De eigenares van de landelijke buurtwinkel beslist in bepaalde situaties om mensen geen alcohol meer te verkopen. En ook de wijkagent geeft aan preventief te werken door er bij nieuwe inwoners op aan te dringen om een contactpersoon door te geven voor noodsituaties.

Of problemen door AB worden doorgegeven aan familie of hulpverleners is zeer afhankelijk van beroep tot beroep. De apothekers en wijkagent hebben door hun beroep frequent contact met de huisarts of OCMW en zeiden indien nodig *signalen* te kunnen doorgeven. De bankfiliaalhouder geeft aan dat dit vanuit zijn beroep vaak onmogelijk is. Eenmalig gaf

hij *informatie* door aan de kinderen bij vermoeden van cognitieve problemen. De andere AB geven aan dat zij een organisatie missen waar zij problemen kunnen signaleren en zien de sociale dienst van het OCMW als aanspreekpunt hiervoor. Tot nu toe ontbreekt er een duidelijk kader over in hoeverre zij hun vermoedens mogen doorgeven. Daarom zoeken ze nu in noodsituaties een oplossing via het eigen netwerk.

AB die door hun beroep vaak in contact komen met zorgprofessionals of professionele hulpverleners zijn sneller in staat om een complexe zaak multidisciplinair aan te pakken. Dankzij een goede samenwerking met huisarts en OCMW kunnen deze AB kwetsbare ouderen toeleiden naar formele begeleiding. Een apotheker illustreert dit als volgt:

> *… omdat die vrouw alleen thuis woonde, ze spreekt de taal niet, Afrikaanse achtergrond, problemen met bepaalde pijnstillers waaraan ze verslaafd is geraakt, een paar keer gevallen, ook omwille van de medicatie die ze neemt. Omdat het op het gebied van communicatie totaal niet vooruitging, is er wel een stap gezet naar meer inkadering. Toen hebben wij samen met de verpleging, de huisarts en een sociaalassistent ons ingezet om te kijken: Hoe gaan wij die begeleiding verzorgen? Hoe gaan wij zorgen dat die medicatie bij die patiënt geraakt? Hoe zorgen wij dat die op bepaalde afspraken komt? Die huisarts heeft toen een dagverblijfcentrum geregeld voor die patiënt. Wij zorgden, in combinatie met die verpleegkundige, dat de medicatie in orde was, tot aan betalingen aan toe. Er werd daar eigenlijk een heel systeem op poten gezet dat voor iedereen wel vol te houden was, zodat die persoon omringd was en wist waar ze terecht kon.*

Het lukt echter niet om alle complexe zorgsituaties op te lossen. *De oudere weigert* soms zelf alle hulp en verschillende hulpverleners krijgen samen ‘het deksel op de neus’:

> *Wij hebben contact opgenomen met de familie die hier niet ver vanaf woont. Zij zeggen ‘oké wij willen ons moeder helpen, maar*

wij geraken daar niet binnen'. De conciërge van het gebouw is al naar de vrederechter geweest. Het probleem is: het is haar eigendom, dus je kunt haar daar heel moeilijk uitzetten. Als je zou zeggen ze sticht brand, dan oké, maar er moet iets ernstig gebeuren voor... Alé... Die graffiti, dat roepen, soms een keer in haar blote door de gang lopen dat is allemaal niet zwaar genoeg om daar in te grijpen. Daar zitten we vast. Zij [sociale dienst] geraken daar ook niet binnen, niemand. (Wijkagent)

Andere knelpunten zijn zorgen omtrent privacy. De bankfiliaalhouder geeft aan over veel persoonsgegevens te beschikken maar gebonden te zijn aan het bankgeheim. Ook apothekers kennen de naam en vaak de gezondheidsgeschiedenis van bepaalde cliënten maar mogen dit vanwege hun beroepsgeheim niet doorgeven aan het OCMW. De andere AB stellen zich al dan niet vragen bij de privacy van ouderen. Daarnaast is er schrik voor de *continuïteit* van dagelijkse activiteiten. Het kunnen vrijmaken van tijd maakt een verschil als je alleen in de zaak staat of met klanten, als de postbode nog veel brieven moeten posten of niet. De angst dat de hoofdtaak verloren gaat of om bemoeizuchtig over te komen en daardoor klanten te verliezen, is een bezorgdheid. Vervolgens geeft men ook aan dat het effectief bepalen of een situatie gedefinieerd kan worden als *zorgtekort* moeilijk is. De kapster aan huis stelt vast dat sommige ouderen nog in primitieve omstandigheden leven maar zich daar gelukkig bij voelen, terwijl buitenstaanders diezelfde woonsituatie als vuil en onhygiënisch beschouwen omdat zij andere normen hierover hebben. Een laatste knelpunt is de juiste balans vinden tussen afstand en nabijheid en grenzen durven stellen. Té dicht bij de oudere staan zorgt voor een onevenwicht in die balans:

Ik heb een week of drie geleden, een klant geweigerd. Die heeft mij dan gestalkt. Die heeft zelfs achter mij gereden met een auto. Dan zeg ik echt van: "Hier stopt het." Ja.
Het was een heel lief madammeke ... maar zij kon zich niet aan de afspraken houden. Eigenlijk daardoor. Ik moet mij aan de afspraken houden, als je aan huis komt. Dat madammeke kon

dat helemaal niet. Dan kom ik binnen en dan begint zij op je gevoel te werken, te kussen en te bepampelen en dingen. Dan heb ik zoiets van: "Oh, nee." Ik ben haar bezit niet. Ja, je hebt er een vertrouwensband mee. Dat klikte heel goed, maar op dat punt vind ik dat wel erg. Het was eigenlijk gewoon … Dat ging niet bij mij. Tien keer veranderen op een week. Alle weken komen en dat moest tien keer veranderen. 's Avonds om tien uur bellen. Zondagavond om elf uur bellen. Ja, dan heb ik wel zoiets van: "Mijn privé, is mijn privé en daar moet je afblijven." Dan zeg ik echt: "Stop." (Kapster)

4.3 Antenneberoepen als sleutel voor doorverwijzing

Binnen de beroepen die voor deze studie werden bevraagd, vindt enkel de bankfiliaalhouder dat hij geen sleutelrol heeft in de doorverwijzing van kwetsbare ouderen naar een hulporganisatie. Een meldpunt waarop hij iemand kan contacteren zou hij daarentegen wel gebruiken in geval van nood. Alle andere AB vinden dat een meldpunt, waar ze met bekommernissen terecht kunnen, nodig is omdat zij nu "op basis van eigen gezond verstand" hulp aanbieden. In de gesprekken met de AB kwam de sociale dienst van het OCMW het vaakst naar voor als contactorganisatie, hoewel de apotheker uit Brussel ook de meerwaarde van vzw's die kwetsbare groepen helpen onder de aandacht bracht. De AB geven een reeks aanwijzingen mee voor het opstarten of het gebruik maken van een meldpunt:

- Omtrent de privacyregelgeving is er een wettelijk kader nodig voor de AB vooraleer kan worden overgegaan tot meldingen.
- Afhankelijk van persoon tot persoon, niet van AB, is er momenteel een voorkeur om een anonieme melding te geven.
- De melding dient opgevolgd te worden op een laagdrempelige manier. Aangezien de oudere door diens kwetsbaarheid moeilijk verschillende diensten binnen een zorg parcours kan afgaan, is het aan de hulporganisatie om de oudere hierbij te begeleiden.

- Voor ouderen die zorg mijden is er eerst vertrouwen nodig. Daardoor vinden sommige AB het belangrijk dat de hulpverlening voor hen traag wordt opgestart.
- Per gemeente zou er één meldpunt moeten zijn met één centraal nummer dat kenbaar gemaakt is bij alle mogelijke AB.
- Raad en suggesties om moeilijke situaties aan te pakken

Zowel binnen de steden als de gemeenten werden drie evoluties zichtbaar die een invloed hebben gehad op het werk van de AB. Een eerste evolutie is de sterke daling van het aantal beroepen met een antennefunctie: buurtbakkers en lokale beenhouwers verdwijnen en veranderen steeds vaker in een supermarkt. Een tweede evolutie is het verdwijnen van het *sociaal kapitaal van de buurt* waardoor de weinige buurtwinkels die sociale functie overnemen:

> *Eliane: Het is niet gemakkelijk voor kleinere winkels. Ik denk … Sociaal contact. Ja. Soms hebben we het gevoel, dat we meer sociaalwerkers zijn, dan dat we …*
> *Helène: Soms moeten we psycholoog zijn, soms moeten we dokter of … Ja. Dat zijn we wel niet, maar … Maar, je maakt het wel mogelijk. Ja. Proberen die mensen een antwoord te geven.*

Een derde evolutie is een verandering in de functie van de AB of de limitatie van het maatschappelijk karakter van het beroep door controle van hogerhand. Door de digitalisering komen bijvoorbeeld minder mensen naar de bank en is er minder tijd aan het loket. Postbodes vervulden vroeger een socialere functie waarbij ze langsgingen bij ouderen. Dit gebeurt nu nog slechts zelden door hogere werkdruk. Desondanks doen zij na of tijdens hun postronde nog boodschappen of helpen ze bij administratieve verrichtingen.

> *Postbode 1: [over ouderen die niet naar de winkel konden gaan] Ik ging daar twee keer per week voor ik vertrok op ronde ging ik eerst langs de bakker want dan moest ik daar twee keer per week een brood afleggen. En briefkes voor naar de apotheker dat deden wij vroeger allemaal, maar die tijd… Ik heb nu 840*

huizen, toen in de tijd had ik er 300. Het is nu echt werken, jagen en jagen om gedaan te krijgen.

Postbode 2: Wij hebben onze adressen waar we al eens langsgaan en dat wordt doorgegeven van den ene postbode op den andere. Als ge [interne] opleiding krijgt en dan kunt ge zeggen daar al eens een tas koffiedrinken. Maar dat is minder en minder dat dat gebeurt. Zo heb ik over het laatst al een doorlopende opdracht voor iemand in orde gebracht.

5 Discussie

Dit onderzoek exploreerde de mogelijkheid om antenneberoepen (AB) in te schakelen in de detectie naar kwetsbare thuiswonende ouderen. Daarbij werden 3 onderzoeksvragen centraal gesteld:

1. Kunnen antenneberoepen kwetsbaarheid bij thuiswonende ouderen detecteren? En hoe doen zij dit?
2. In welke situatie ondernemen zij actie als ze kwetsbaarheid met een zorgtekort bij thuiswonende ouderen detecteren en welke knelpunten komen voor bij deze acties?
3. Welke ondersteuning is belangrijk om de rol van antenneberoep op te nemen?

De resultaten tonen aan dat AB verschillende vormen van kwetsbaarheid kunnen detecteren. Verschillende voorbeelden van cognitieve, fysieke, sociale, psychische en omgevingskwetsbaarheid kwamen aan bod. Daarnaast werd ook financiële kwetsbaarheid aangehaald, een domein dat niet in de courante multidimensionele kwetsbaarheid conceptualisaties is opgenomen (De Roeck e.a., 2018; De Witte e.a., 2013; Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010; Steverink, Slaets, Schuurmans, & van Lis, 2001). Bepaalde vormen zoals fysieke kwetsbaarheid zijn visueel duidelijk waar te nemen, terwijl andere vormen zoals cognitieve en psychische kwetsbaarheid dat minder zijn. Voor cognitieve kwetsbaarheid ervaren AB wel dat er bepaalde alarmsignalen zijn zoals

vergeetachtigheid. Soms komen verschillende vormen van kwetsbaarheid, die leiden tot complexe zorgsituaties, samen voor.

Er werden zes types van acties geïdentificeerd: informatie geven, advies geven, extra diensten aanbieden, luisteren naar het verhaal van de klant/cliënt, preventief handelen en signalen doorgeven. Het ondernemen van een bepaalde actie is sterk afhankelijk van het soort beroep. Sommige acties zijn bijna standaard onderdeel, mits een ruime invulling, van het takenpakket van het beroep: vb. advies geven is een taak van de bankfiliaalhouder en de apotheker, of goederen leveren aan huis is een opdracht voor de handelaar. In functie van het specifieke doelpubliek (i.e. kwetsbare ouderen), gaan ze dan ook hun opdracht specifiek invullen. Sommige acties zijn altruïstisch: Luisteren naar iemands verhaal werd eveneens als een actie beschouwd en hoort bij het sociale karakter van het beroep. In bepaalde situaties gaat het zo ver dat AB taken extra gaan doen die niet verwacht worden zoals het helpen bij financiële verrichtingen.

Vijf verschillende knelpunten om actie te ondernemen werden meegenomen uit de gesprekken met AB. Voor het doorgeven van problemen wordt het eigen netwerk ingeschakeld, maar de meeste AB gaven enerzijds aan dat zij een organisatie missen waar zij met een probleemsituatie terecht kunnen en anderzijds wat de regels omtrent privacy hiervoor zijn. In België is het OCMW de gepaste instantie waar AB terecht zouden kunnen voor een melding, maar de zorgen van de deelnemers aan dit onderzoek over de privacyregels zijn terecht. De Europese wet stelt dat de AB steeds de toestemming van de betrokkene nodig heeft voor zijn persoonsgegevens mogen worden doorgegeven aan een instantie zoals het sociaal huis of het OCMW[1].

[1] Verordening (EU) 2016/679 van het Europees Parlement en de raad van 27 april 2016 *betreffende de bescherming van natuurlijke personen in verband met de verwerking van persoonsgegevens en betreffende het vrije verkeer van die gegevens en tot intrekking van Richtlijn 95/46/EG* algemene verordening gegevensbescherming, Deze tekst kan geraadpleegd worden via volgende link https://eur-lex.europa.eu/legal-content/NL/TXT/?uri=CELEX%3A32016R0679

Naast privacy kwamen nog vier andere knelpunten aan bod: zorgweigering, continuïteit dagelijkse activiteiten, inschatten zorgtekort en balans tussen afstand versus nabijheid. Zorgweigering op latere leeftijd kent zijn oorzaak vaak binnen complexe zorgsituaties (Lange, 2014; Geelen & Aarnoudse, 2011) of bij een sterke wil om de eigen identiteit te blijven behouden, wat een langdurige opvolging vraagt (Corvol, Balard, Moutel, & Somme, 2014). Het belang van continuïteit werd afzonderlijk door verschillende AB naar voren gebracht. De hoofdtaak van het beroep mag niet in het gedrang komen door op te treden als antenneberoep. De twee laatste knelpunten hebben een sterke betrekking op het persoonlijk referentiekader van de AB. Het inschatten van een zorgtekort kan delicaat zijn, want wat kwetsbaar lijkt voor een buitenstaander, is voor de oudere eventueel normaal. Het is belangrijk om ouderen zelf de regie te laten behouden (Broese van Groenou, 2011) en zelf te laten beslissen waar hulp nodig is, hoewel hoewel dat op grenzen kan stuiten zoals het zelf organiseren van zorg (Eskens & Hoogakker, 2015). De balans vinden tussen afstand en nabijheid is ook sterk afhankelijk van persoon tot persoon. Idealiter is er professionele nabijheid die in de gezondheidszorg vaak naar voren wordt geschoven om de juiste balans te vinden tussen enerzijds het empathisch zijn en betrokken blijven en anderzijds genoeg ruimte overlaten om objectief te blijven (van Staveren, 2017).

De laatste onderzoeksvraag focuste op de noden van AB en welke ondersteuning belangrijk is om de rol van antenneberoep op te nemen. In de toekomst rekenen AB voor ondersteuning op één meldpunt dat er per gemeente zou moeten zijn. Momenteel ontbreekt hier echter nog een wettelijk kader inzake de privacy voor. Onrechtstreeks kwamen uit de analyses nog noden voor de ouderen aan het licht die gerelateerd zijn aan de AB. In deze studie werden deze beschreven als drie evoluties. De eerste en tweede evolutie focussen op de rol van de buurtwinkel zoals een kruidenier, bakker of apotheek. Enerzijds is er meer nood aan buurtwinkels. Door het verdwijnen van deze handelaars zijn ouderen genoodzaakt om verder van huis boodschappen te doen of moeten zij hulp hiervoor zoeken van derden (Buffel, Demeere, De Donder, & Verté, 2011). Anderzijds is de zeldzame buurtwinkel die nog overblijft de plaats bij uitstek voor sociaal contact, aangezien ook het sociaal kapitaal van de buurt in sommige plaatsen daalt. Buurtwinkels zorgen naast de voorziening van levensmiddelen ook voor buurtverbondenheid en ze zorgen er ook voor dat mensen op de hoogte blijven wat er in de buurt gebeurt (Buffel, e.a,

2011). Bepaalde grootwarenhuizen nemen nu al de eigenschappen van de vroegere buurtwinkel over door koffiecorners te installeren. Andere voorbeelden uit Ierland (McDonald, Scharf, & Walsh, 2018) en New York (Goldman, Owusu, Smith, Martens, & Lynch, 2016) zijn de leeftijdsvriendelijke ondernmeningen of age-friendly businesses waar trainingen worden gegeven aan geïnteresseerde zaakvoerders en bijvoorbeeld assistentie aan ouderen tijdens het winkelen wordt voorzien. De implementatie van detectie van kwetsbare ouderen kan het concept van age-friendly businesses verrijken.

Een derde evolutie situeert zich bij veranderingen op het macroniveau die een grote invloed hebben op ouderen als individu. Volgens de 'political economy theory of ageing', worden de status, de middelen en de levensloop van een oudere bepaald door iemands woonplaats, maar ook de sociale structuur waarin de oudere leeft die op zijn beurt beïnvloed wordt door economische en politieke factoren (Estes, Swan, & Gerard, 1982). Verhalen van AB tonen aan dat veranderingen binnen het beroep (vb. bij Bpost en banken) ervoor zorgen dat er minder tijd is voor de klant of cliënt. De geïnterviewde AB waren gereserveerd in het meedelen van de achterliggende oorzaken hiervoor. Een mogelijke oorzaak is de steeds verdere privatisering van Bpost, ooit een overheidsbedrijf, en het dalend aantal andere dienstverleningen in landelijke gemeenten zoals bankkantoren (D'Hondt, 2017). Toenemende veranderingen op macroniveau, fusionering en verdere digitalisering lijken geen zorg te zijn voor vitale ouderen, maar voor kwetsbare ouderen des te meer.

Met deze studie hebben we een reeks belangwekkende kenmerken maar ook bezorgdheden van AB genoteerd. Toch willen we ook wijzen op enkele tekortkomingen van deze studie. Door het exploratieve karakter van de studie lag de focus op verkenning van informatie bij verschillende soorten AB en werd niet tot in de diepte doorgevraagd naar ervaringen, meningen of gevoelens van één specifieke groep AB. Deze studie is dan geen limitatiteve opsomming van alle mogelijke AB. Er zijn nog tal van andere AB die niet werden opgenomen in deze studie. We denken hierbij nog aan beroepen zoals marktkramer, slager, restaurant/caféhouder, dierenarts en mogelijks nog vele andere. We geven tenslotte ook mee dat ook niet-professionals - zoals mensen uit het verenigingsleven, actieve buurtvrijwilligers, pastoors, imams of andere geestelijken - een sleutelfunctie kunnen hebben in de detectie en doorverwijzing van kwetsbare ouderen. De resultaten uit

deze studie tonen aan dat er een wil is bij AB om kwetsbare ouderen door te verwijzen naar OCMW's en welzijnsorganisaties. Verder onderzoek moet echter de effectiviteit en haalbaarheid hiervan uitwijzen.

6 Conclusie

Met de informatie uit deze studie hebben OCMW's en welzijnsorganisaties een basis om een beleid uit te werken omtrent de inschakeling van antenneberoepen in de detectie naar kwetsbare ouderen en de ontwikkeling van een meldpunt voor deze beroepen. Deze professionals zien door hun dagelijkse beroepsactiviteiten verschillende vormen van kwetsbaarheid bij hun klanten of cliënten. Zij nemen zelf beperkt actie wanneer nodig, maar hebben nood aan ondersteuning en een duidelijk kader over de mogelijkheden wanneer ze een situatie willen melden. Professionals die kwetsbare ouderen als klant of cliënt hebben beschikken over veel waardevolle informatie die gebruikt kan worden om verdere kwetsbaarheid te voorkomen.

English abstract

Background: When older adults have early symptoms of frailty, research indicates that an early intervention can delay or avoid adverse frailty outcomes such as hospitalization or institutionalization. Frailty is to date mostly detected in a medical setting. General practitioners or home care nurses are care professionals who are the key persons in this detection. The informal network of frail older people as well has a crucial role in avoiding the worsening of frailty and the prevention of adverse frailty outcomes. Unfortunately, not all older adults in need of care have adequate care networks. In the past years, many policies have seriously invested in prevention and intervention programs for frail older adults. Within the D-SCOPE study, the potential role of 'non-care professionals' is explored for detecting frail older adults without an informal network and potentially leading them to formal care. Professionals such as pharmacists, mailmen or cashiers have frequent contact with frail older adults and can be seen as "antenna professionals" given they receive considerable information from

their clients or costumers. This explorative study researched (a) whether antenna professionals can detect frail community-dwelling older adults, (b) which action they undertake when they detect a frail person and which barriers may occur to initiate an action and (c) which support is needed to be an antenna professional.

Methods: 18 persons with different professions were interviewed: pharmacists, police inspector, bank clerk, mailmen, local business owners such as florist and grocer, manager from a hair salon or supermarket and more. Professionals who didn't had contact with frail community-dwelling older adults during their work were excluded for an interview. Participants were asked to what extend they had contact with frail older adults who were according to them in need for help, if they ever referred them towards appropriate care, what an antenna profession meant to them, what support they need to act as one and which barriers one can expect for this kind of function. All interviews were thematically analyzed.

Results: The professionals could detect frailty in numerous ways. Physical frailty was visually noticeable and by starting conversations, other psychological and social frailty became visible while practicing the profession. Not seldom older adults themselves shared tragic stories of their lives. Cognitive frailty was recognized with alert signs, for example when older adults came to buy the same item twice. These professionals regularly initiate actions that were sometimes linked to their profession such as giving advice or delivering groceries. Just listening to the story could also be seen as an action for helping frail persons. In specific cases, situations were passed towards healthcare professionals or relatives. Barriers for referring frail older adults towards care organizations were concerns about privacy, fear of losing the continuity of the daily activities, correct estimating if one in fact needed help and finding a the right balance between professional and personal life. Most participants in the study thought they could act as an antenna function for referring towards professional care although they are most concerned about the privacy regulation on this matter. One central contact point in the

community for referring frail older adults was believed to be a solution to prevent frailty worsening and the question to mention this anonymously was more than once raised. More concerns of the possible antenna professionals were found in three evolutions that were analyzed across the interviews. A first was the disappearance of local business owners in the community. A second was the decline of neighborhood social capital, which makes older adults increasingly turn to neighborhood stores for social contact. A third evolution is the transformation of the social character of antenna profession in a digitized world or higher work pressure.

Discussion and conclusion: The findings illustrate that professionals can have an antenna function in the detection of different types of frailty. To use the information of these professionals, their concerns should sincerely be acknowledged. Not only was correctly estimating if one effectively needs help a concern, also privacy issues were discussed. Referring a frail person with care needs anonymously is straightforward not possible according to the European Union regulation on the protection of natural persons with regard to the processing of personal data. Therefore, all professionals must have the permission of the older adult before referring him or her to a care or welfare organization. It should be noted that this study was explorative and possible other persons with an antenna function such as members from clubs or societies for older adults, neighborhood volunteers, priests or Imams were not included in this study and could have an important antenna function as well. The findings of this study however provide a basis for care or welfare organizations in the development of a policy towards the implementation of professionals with an antenna function for detecting frail community-dwelling older adults. These professionals already have valuable information that can be used to prevent frailty worsening.

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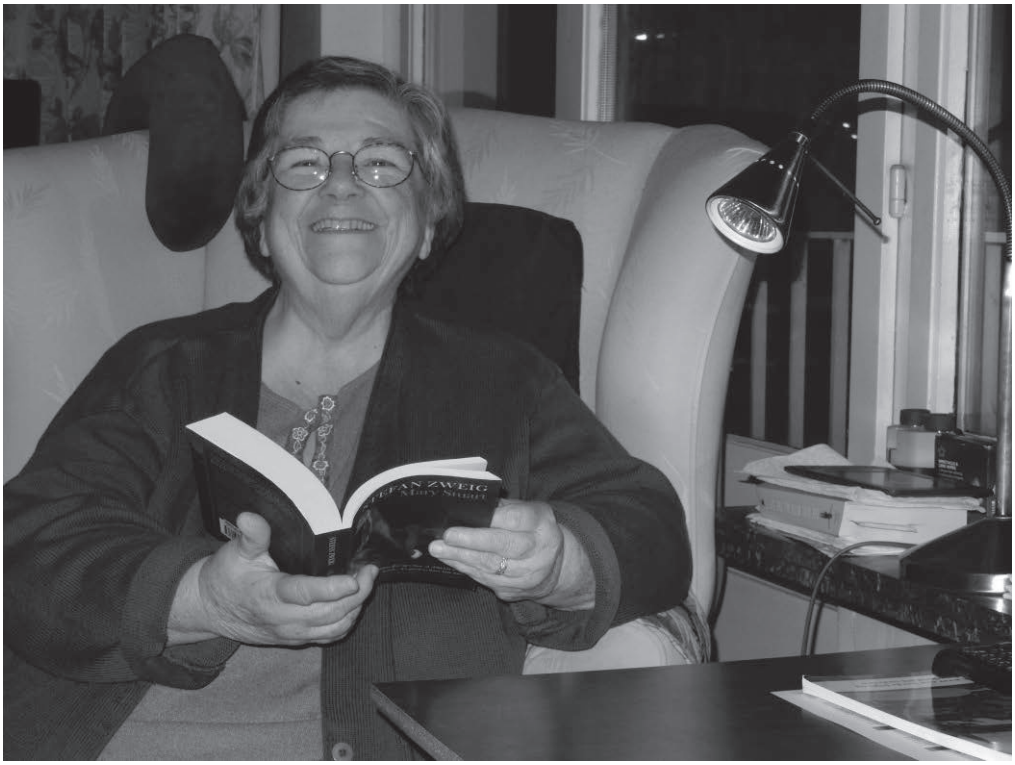


PART IV – DISCUSSION SECTION

CHAPTER 10

GENERAL DISCUSSION, LIMITATIONS, DIRECTIONS FOR FURTHER RESEARCH AND IMPLICATIONS FOR POLICY AND PRACTICE

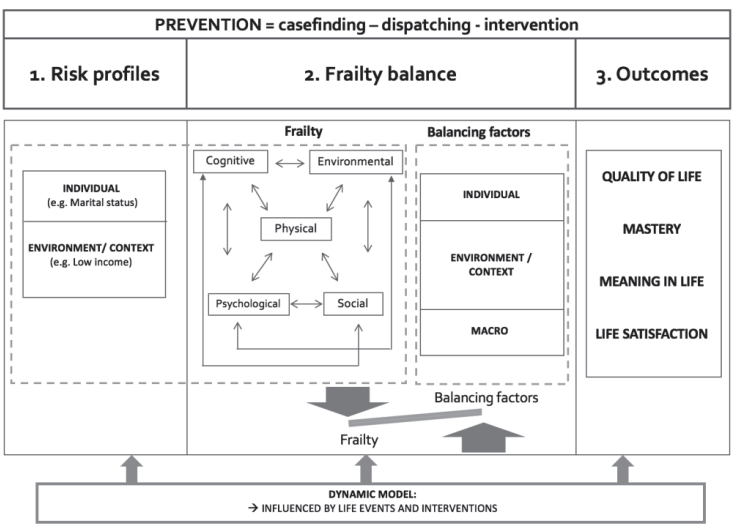
1 Abstract

This chapter presents an overview of the main research objects of this dissertation and the most remarkable findings of the study. In addition, the methodological and conceptual limitations of the studies. This chapter ends with directions for further research and considerable policy implications.

2 Overview of the research objectives and results

This dissertation focused on two main research aims that received too little attention in ageing or frailty research and are deemed essential to age well. The first research aim concentrated on the increase of knowledge of positive frailty outcomes. The second aim was directed towards the relationship between the social environment of older adults, frailty and frailty outcomes. Both research aims were further divided in particular research aims for each study, which in turn had one or more research questions. An overview of the results is given below, for each main aim separately. This section does not purely restate the results from the former chapters, although findings are highlighted and discussed within the bigger structure of the dissertation and the overall conceptual D-SCOPE model.

Figure 10.1: Overall conceptual model of the D-SCOPE project



2.1 Aim 1: More knowledge on positive frailty outcomes

Notwithstanding the majority of frailty research focuses on physical frailty and adverse frailty outcomes, findings of these studies indicate that older adults experience frailty by more than one domain. Moreover, the evidence of these papers suggests that positive outcomes are worthwhile to be considered in research on frailty in later life. As earlier mentioned, in general research on outcomes is concentrated around adversities such as morbidity, hospitalization, institutionalization and mortality (e.g. Eagles, Yadav, Perry, Sirois, & Emond, 2018; Vermeiren et al., 2016) and very little previous research was carried out on positive outcome. Non-frailty ageing research includes a broader range of outcomes, including physical functioning, mental well-being, social functioning, successful ageing or healthy ageing (Peel, Bartlett, & McClure, 2004). In the purpose of the D-SCOPE project, guided by international literature and the experiences of frail older adults themselves, several positive outcomes were detected in the qualitative narratives of older people and they were used in the questionnaire of the third phase of the general D-SCOPE project.

The third chapter portrayed a general overview of the experience of frailty and well-being by older adults in a guaranteed 24-hour care project. These older adults experienced frailty in a number of different domains, which included the five domains that are used in the D-SCOPE studies (i.e. physical, psychological, cognitive, social and environmental frailty) yet also other types were found: such as financial problems, dealing, ageism and experiencing literary and administrative difficulties in a rapidly changing digital world. Despite being frail according to the Comprehensive Frailty Assessment Instrument (CFAI), frail older adults do not necessarily feel frail. We found that older adults often compared themselves with other frailer persons which increased their self-esteem. Whereas the majority of frailty studies focus on adverse frailty outcomes, this study demonstrated that frail older adults still experienced high levels of well-being. Along with frailty, well-being was experienced in many different ways. Four factors that contributed to well-being were explicitly formulated by frail older adults who received professional care. The first was *sense of* mastery, that comprised having control on events in their life, having the opportunity to make their own choices and being independent as much as possible. The second was *meaning in life*, often described

by frail older adults as having a meaningful life and experiencing a sense of coherence. A third factor contributing to well-being was the *feeling of inclusion*, either in a family context or on a neighbourhood or societal level. Fourth, the ability to *age in place* was emphasized. At last, balancing factors for frailty and well-being were identified which constructed the conceptual D-SCOPE model (Figure 10.1).

In chapter four (Study 2), the attention was aimed at one specific domain of well-being (i.e. meaning in life) and one specific domain of frailty (i.e. social frailty). In consideration of the advantages of meaning in life in later life (Battersby & Philips, 2016), the seven needs for meaning according to the integrative conceptual model of Derkx were used in this study (Derkx, 2013; Derkx, 2015). As an important source for meaning in life in older adults is found in social relationships (O'Donnel et al., 2014; Stillman & Lambert, 2013) it was explored how socially frail older adults experience meaning in life or a lack thereof. The results indicate that despite being (assessed as) socially frail, the older respondents did experience meaning in life: the need for purpose, moral worth, competence, self-worth, coherence, connectedness and/or excitement. While ageing, a loss of meaning in life was experienced in three of the seven needs for meaning. Lack of purpose, lack of coherence and a shortage of connectedness were illustrated as a result of life events such as the death of a spouse. There were participants in this study who spoke about a life filled with misery. Nonetheless, even then, they experienced meaning in life as at least one need for meaning was satisfied.

In chapter 5 (Study 3), the first goal was to examine how we could include these positive outcomes in a quantitative questionnaire. To minimise respondent burden due to fatigue, a considerable issue given frail older adults are in the target group, the second goal was to develop a short questionnaire. 15 items of four existing scales on positive frailty outcomes and two self-constructed items were used to construct a Short Well-being Instrument for Older adults (SWIO). Two self-constructed items, based on qualitative interviews of the second D-SCOPE phase (Dury et al., 2018) and items from the sense of mastery scale (Pearlin et al., 2007), meaning in life questionnaire (Steger et al., 2006), the satisfaction with life scale (Diener et al., 1985) and the community integration measure (McColl et al., 2001) were used in the development of this scale. Three subscales with

three questions on a five-point Likert scale remained in the final questionnaire measuring sense of mastery, meaning in life and life satisfaction. In a cross-validation, all scales showed good internal consistency. In an external validation, zero-order correlations showed negative correlations between different frailty dimensions and the outcome measures. Positive correlations were found between the outcomes measured with the SWIO and numeric rating scales on quality of life, meaning in life, sense of mastery and community inclusion.

Although participants of the D-SCOPE study were asked how they experienced their quality of life, this outcome was not included in the studies used for this dissertation and the development of the SWIO. Quality of life measurements are often used in gerontological research (e.g., Hyde, Wiggins, Higgs, & Blane, 2003; Lin, Li, Lin, & Chen, 2016; Scholzel-Dorenbos et al., 2007) and excellent measures do exist to evaluate someone's quality of life. There was however too much overlap between these instruments and other D-SCOPE measures. The WHOQOL-BREF, a brief measurement (BREF) by the World Health Organization (WHO) about quality of life (QOL) (The WHOQOL Group, 1998) has extensive overlap with the original CFAI. The CASP-19 (Control, Autonomy, Self-realization & Pleasure), another high valued and much used instrument to measure quality of life (Hyde, Wiggins, Higgs, & Blane, 2003), showed overlap with the sense of mastery scale.

Lastly, the SWIO is not just an instrument amidst many other that measure psychological or subjective well-being. The instrument is, for example, shorter than the frequently used Well-Being Questionnaire 12 (W-BQ12) and more extensive than the WHO-5 Well-Being Instrument or the WHO-10 Well-Being Instrument (Bech, Gudex, & Johansen, 1996; Topp, Østergaard, Søndergaard, & Bech, 2015) by capturing three separate domains of well-being. Comparable to the other short well-being instruments, the SWIO is best applied as a screening tool for well-being in a frail older population. In case a general examination of well-being is needed, the comprehensive Ryff Scales of Psychological Well-Being (Ryff & Keyes, 1995; Ryff, 2014) are more appropriate.

The results from these three studies (Duppen, De Donder, Verté, & Machielse, 2017; Duppen et al., 2018; Duppen, Rossi, Dierckx, Hoeyberghs & De Donder, under review),

together with other D-SCOPE research (e.g., Dury et al., 2018; van der Vorst et al., 2017) delineate the added value of researching positive frailty outcomes than focusing on adversities alone.

2.2 Aim 2: the relationship between the social environment and frailty in later life

Earlier research has highlighted that human ageing has been decontextualized and separated from the environment (Peace et al., 2007). Both the social and living environment however are important for older people's health (Annear et al., 2014). The living environment can be a vital place for older adults. It is not only the place where people live, but where they have connections with their community, friends and family (Beard et al., 2016; WHO, 2015, Pruchno, 2018) to whom older adults can rely on for social support (Krause, 2003). This type of support can be defined as community care and is highly appreciated by older adults (Eckert, Morgan, & Swamy, 2004), and is encouraged by local policy makers (Keating, Otfinowski, Wenger, Fast, & Derksen, 2003). The systematic review on the social environment's relationship with frailty (study 4) revealed that social environmental factors are only rarely included in frailty research. Findings from 15 studies pointed out that having social support or social networks showed contested results. However, if studies included social participation, subjective neighbourhood experience, and socioeconomic neighbourhood characteristics results were unequivocal: these social environmental factors are related with frailty or adverse frailty outcomes.

With this knowledge, chapter 7 (Study 5) in particular focused on the relationship between frailty and social participation. In-depth qualitative research was conducted to find how frail older adults socially participate. Using Levasseur and colleagues (2010) differentiated levels of activities, three out of four levels of social participation (Levasseur, Richard, Gauvin, & Raymond, 2010) were identified in the narratives of 38 severely frail older adults. Most activities mentioned by participants were centred around the *interacting with others* level and *doing an activity with others* level. Although being frail, few participants mentioned also activities in the *helping others* level. Changes in the physical condition (e.g., disabilities) the physical environment (e.g., disappearing of local stores) and the social environment (e.g., network decline) were accountable for disengaging from social

activities. Meanwhile, social environmental factors such as places in the community were people meet, the formal or informal network were found to maintain and increase frail older adults' wellbeing and act as a catalyst for social participation which is in line with results from chapter 6 (study 4).

One of the remarkable findings in chapter 7 was the concept of low-key participation. Low-key participation was earlier described in German studies as *Subtile soziale Partizipation* with a relation to life satisfaction (Kaspar, Oswald, & Hebsaker, 2015; Nauman, 2006). A comparable conceptualization can be recognized in the work of Belgian anthropologist Ruth Soenen on *het kleine ontmoeten* or 'small encounters' in English (Soenen, 2006). In the work of Levasseur et al (2010) on different levels of activities, the third level encompasses 'Interacting with others (social contact) without doing a specific activity with them'. (Levasseur et al., 2010). The findings of our study demonstrate that that this level can be further expanded with low-key participation.

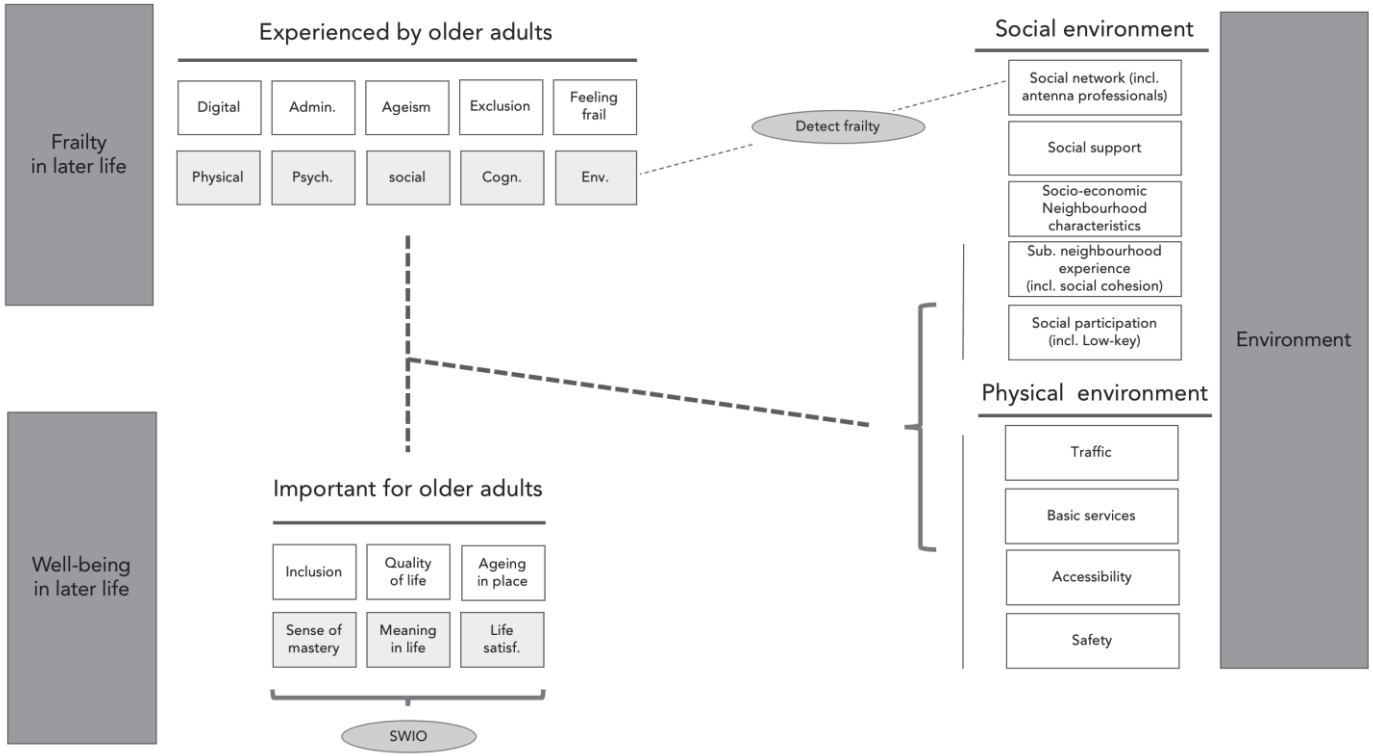
Results from the aforementioned studies were included in the development of the third phase of the D-SCOPE project. In chapter 8 (Study 6), these data were used to research the relationship between frailty and 3 dimensions of well-being (i.e., sense of mastery, meaning in life and life satisfaction), within a person-environment fit model. In a sample of 869 older adults with a frailty risk profile, general linear models showed (a) a relationship between frailty and lower levels of well-being, (b) a relationship between both physical and social environmental factors and higher well-being and (c) 9 moderating effects of the environment to the relation frailty – well-being. Low-key participation moderated the relationship between psychological frailty and meaning in life and between environmental frailty and life satisfaction. Low traffic in the neighbourhood in its turn showed higher levels of meaning in life for environmental frail older adults. Negative interactions were found for the presence of basic services and all dimensions of well-being for psychologically frail older adults and with life satisfaction for cognitively and physically frail older adults.

Recent empirical research indicates that environmental conditions have a great infuence on the withdrawal from public spaces (Wanka, 2018). The creation of age-friendly environments remains therefore an important strategy to improve well-being from a collective perspective. Although not all problems can be resolved by implementing age-friendly environments. Despite the fact that an age-friendly neighbourhood important is,

especially for frail older adults (Cramm, van Dijk, & Nieboer, 2018), and that higher levels of well-being were found for most frail older adults when they lived in a better or more age friendly environment according to chapter 8 (Study 6), it does not imply that it improves well-being. It remains necessary to tackle frailty at the individual level and to see age-friendly environments as a substitute to obtain better well-being in later life.

In the chapter 9 (Study 7), the possibility to include local professionals in the detection of frail older adults was explored. In the detection of frailty in community dwelling older adults, formal and informal caregivers in the social network of older adults have a key-role to detect frailty in an early state. Results of the last study indicated that non-care professionals have frequent interactions with their older clients and can also have a role in detecting frailty when an informal network around the older person is absent. They are willing to refer frail older adults towards care organisations, although barriers for referring frail older adults towards care organizations were concerns about privacy, fear of losing the continuity of the daily activities, correct estimating if one in fact needed help and finding a right balance between professional and personal life. To include these antenna professionals as fully-fledged actors in the casefinding strategy for D-SCOPE, it might be too early. A new project on this strategy can determine the actual value of these persons in the detection of frail older adults in order to refer them to professional care. In such project, a suggestion is to add other possible key-persons in the social environment of the older adult such as members from clubs or societies for older adults, neighborhood volunteers, priests or imams.

Understanding not only the physical, but also the social living environment of older adults is important because they are places for optimizing interventions (Pruchno, 2018). The results of chapter 6 to 9 contributed to the larger D-SCOPE project, to the knowledge on frailty in later life and towards better understanding in the context of ageing (Pruchno, 2018).



3 LIMITATIONS OF THE DISSERTATION

Several limitations of the dissertation should be considered. Both critical reflections on conceptual approaches as methodological quality will be discussed.

In this dissertation, a range of concepts were used that are debatable. The first concept that is widely discussed is *frailty*, both on its conceptualization as its operationalization (Gobbens et al., 2010). A recent systematic review on physical frailty instruments included not less than 94 different instruments (Azzopardi et al., 2018). In general, there are two approaches in working toward a definition of frailty. Researchers either (a) keep searching to reach a consensus on a conceptual definition or (b) accept that there are different definitions on the subject and as a result demonstrate which definition is most suitable for use (Rockwood, 2005). Out of multiple different definitions, the D-SCOPE research group applied the most comprehensive multidimensional conceptualization and measured frailty with the CFAI-plus (De Roeck et al., 2018) which is most suitable for use in community dwelling older populations. Although all frailty instruments target vulnerable older adults, the research population might have been different if another instrument was used.
From the narratives of older adults in chapter 3 (Study 1), according to them, not being able to deal with burdens such as financial problems and digital illiteracy were considered as frailty. Correspondingly, the professionals who were interviewed in chapter 9 (Study 7) – the antenna professionals – reasoned about a similar, broad range of frailty domains. The question can be raised if these problems should be incorporated the D-SCOPE frailty model as a separate frailty domain, if they should be seen as life course health determinants and risk factors of frailty (Feng et al., 2017) in accordance to the conceptual frailty model of Gobbens (Gobbens et al., 2010), or if they should they be seen as a balancing factors for frailty. A D-SCOPE paper has found that financial problems are an important risk factor for frailty (Dury et al., 2016), yet our own findings demonstrate that financial difficulties generate a frailty-feeling as such as well. Our conclusion would be to include it both as risk factor, frailty domain and balancing factor, depending on the situation. This links back to a discussion in Dutch 'frailty'-literature: in the Dutch language, frailty and vulnerable are words that are synonyms (kwetsbaarheid) contrarily to the English

language where frailty is more seen as a *weakness* and vulnerability has a much broader meaning.

A second concept that is open for debate is the *social environment*. There is currently no clear taxonomy of the dimensions of the social environment (Buffel et al., 2012). The dimensions that were adopted in this dissertation followed directly from the dimensions that emerged in the systematic review (Duppen et al., 2017). Other dimensions might have given other insights.

A third concept that is open for discussion is *meaning in life*. Participants in the second phase of the D-SCOPE project were asked what gave meaning to their life. We found that the participants sometimes lacked the language to explain what gave meaning to their life. This experience is also described in the work of Baumeister who states that "People are quite capable of living happily in modern society without any coherent or explicit philosophy of life" (Baumeister, 1991, p. 26). The conceptual model of Derkx that was used in chapter 4 (Study 2) provided a valuable theoretical model to frame for frail older adult's meaning in life (Derkx, 2013, 2015). To date however, there is no validated scale that uses this framework of Derkx in the measurement of meaning in life. Therefore, the 'presence' subscale from the Meaning in Life Questionnaire (Steger et al., 2006) was used in chapter 5 (Study 3) and chapter 8 (Study 6). One limitation is that only the presence subscale was used while ignoring the 'search' subscale. A second limitation is that the scale was originally validated in a younger population (Steger et al., 2006), although it was later used in several ageing studies (e.g., Battersby & Phillips, 2016; Van der Heyden, Dezutter, & Beyers, 2015). Also, other instruments exist to measure meaning in life and results could have been different if these were used.

For the studies with a qualitative design, several researchers conducted the interviews. and there may have been inconsistencies between interviews. Also, during the interviews, a relative was occasionally present or nearby, which is a possible source of bias as socially desirable responses might have been given. The qualitative studies were part of the second phase of the D-SCOPE project, which had a mixed method design. The participants

first completed a quantitative part including the Montreal Cognitive Assessment. Response bias could have occurred in the later qualitative part due to fatigue (Kieruj & Moors, 2013). For the quantitative studies, data was gathered in three municipalities with the assistance of older volunteers. While participatory research has proven its added value in gerontological research (De Donder et al., 2014) and the volunteers received training, response bias might have occurred due to unfamiliarity of the questionnaire or the target population. Furthermore, all participants lived in a densely populated urbanized Belgian municipality. As environmental characteristics such as accessibility and social cohesion differ between rural and urban areas (van den Berg, Sharmeen, & Weijs-Perree, 2017), the findings cannot be generalized to rural areas or larger metropolitan cities.

4 DIRECTIONS FOR FUTURE RESEARCH

The above-mentioned results and limitations provide several opportunities and directions for further research.

A first major direction for further research concerns the positive frailty outcomes for the most vulnerable frail older adults. More research is needed to examine how psychosocial vulnerable older adults experience their meaning in life. Battersby and Phillips (2016) conclude that the presence of meaning in life may be an important focus when working with psychosocial vulnerable older adults. The experience of meaning in life has a protective factor as it empowers people and creates resilience against the misfortunes experienced by older adults (Ryff & Singer, 1998). While theory on meaning in life has developed apace, empirical research has failed to keep up with these developments, creating a significant gap between rich but abstract theories and empirical tests of them (Park, 2010). In addition, meaning in life is usually approached from a micro perspective. Several authors, however, discuss the multileveled nature of ageing or the micro vs. meso/macro theorizing dimension. A micro level perspective implies that ageing problems originate from or exist within the individual. An older adult has psychosocial problems, on the basis of individual impairments, deprivation or deficits. A micro-perspective focuses upon the individual aspect of ageing and attributes bio-psycho-social deprivations to the individual (Estes et al., 2003). Consequently, it states that problems that arise when ageing derive from individual problems in personal adjustment rather than from structural

inequalities (Achenbaum 2009; Estes et al., 2003). Dillaway and Byrnes (2009) criticize this perspective as individuals are not always able to overcome personal barriers themselves. Such a micro-perspective ignores the inequalities among the ageing population, and the 'ways in which society's structural and social forces advance opportunities for some and limit them for others' (Martinson & Minkler 2006, p. 321). Conversely, including a meso/macro level perspective implies that the impact of the wider social environment, such as social networks, family, but also broader structures, such as state and economy influence ageing. Besides, it also pays attention to, for example, sociological and critical perspectives, feminist theory or political economy (Bengtson et al., 2009). Hagestad and Dannefer (2002) criticize the predominant focus on the micro-level and they use the term of 'microfication' to denote a trend in ageing studies which concentrates on psychosocial characteristics of older adults in micro interactions, thereby neglecting the meso/macro-level. Viewed from the latter perspective, psychosocial problems are not the attribute of the individual. Instead it is created by social and structural conditions. Further research should examine both the micro factors and meso/macro factors in their relation to meaning in life.

A second major opportunity is to investigate more the moderating role of the social environment. As reported in the systematic review (study 4), social participation, subjective neighbourhood experience, and socioeconomic neighbourhood characteristics results are related with frailty or adverse frailty outcomes. This Phd however only focuses on social participation and the subjective neighbourhood experience. With the help of a master student in educational sciences of the Vrije Universiteit Brussel, preliminary research was conducted to research whether socioeconomic neighbourhood characteristics (such as neighbourhood deprivation) was related to different domains of frailty. Analogue to the United Kingdom indices of Multiple Deprivation (IMD), a new deprivation index with five indicators (e.g., employment rate) was created and later linked to a Flemish postal code in order to find a relation with different frailty domains. No significant results were found in the master thesis. An explanation for this result is that in contrast to the UK, there are no indicators available for Belgian areas on a neighbourhood level, only on municipality level. This needs further exploration.

In addition, also the role of social participation could be further examined. This dimension of the social environment was excluded on purpose in the quantitative study (chapter 8). In total, eight types of social participation (e.g., volunteering, informal caregiving, cultural participation) were included in the D-SCOPE questionnaire, but a paper on this topic is currently developed by another researcher of the Belgian Ageing Studies.

A final direction for further research is focused on including the life-course perspective. The cumulative impact of health inequities across the lifespan have a strong influence on healthy ageing (World Health Organziation, 2015). Both quantitative and qualitative research can provide new insights between changes in the social environment throughout the life course and the relationship with frailty. A first possibility is the inclusion of the biomarker allostatic load – known as "the wear and tear" of the body – which is also related to frailty (Gale, Booth, Starr, & Deary, 2016). However, a sole quantitative focus on the life course leads to a fragmented picture while losing a fuller picture of the person (Smith, 2010). Current life course research mainly focuses on quantitatively examining later life conditions such as inequalities in terms of health (Barban, 2013), wellbeing (Vanhoutte & Nazroo, 2016), financial wellbeing (Vandecasteele, 2010) and changes in social relations (Cornwell et al., 2014). In contrast, scarce attention is given to the lived experiences or the experienced life course (McAdams, 2005; Komp & Johansson, 2015), pointing towards the importance of qualitative methods exploring the experienced life course. A sole quantitative focus on the life course leads to a fragmented picture while losing a fuller picture of the person (Smith, 2010). Therefore, also qualitative research on this topic is needed.

5 IMPLICATIONS FOR POLICY AND PRACTICE

"I am surprised how little knowledge of academics is translated to the field elderly care and I wonder if academics know what our biggest needs are." These were the words from a manager in a long-term care facility who was involved in the stakeholder sessions of the D-SCOPE project. Fortunately, the D-SCOPE project has a valorization trajectory in order to translate as much results from the project towards the field of practice. Specifically, for this dissertation, following implications are valuable for policy and practice.

5.1 Prioritizing ageing *well* in the *right* place

Many older people have the desire to grow old in their familiar environment (Löfqvist et al., 2013; Smetcoren, 2016). When care dependent older adults age in place, they receive care from informal caregivers or a combination of formal and informal caregivers (Eckert, Morgan, & Swamy, 2004; Lambotte et al., 2018) and sometimes, long-term care at home is only achievable when help from relatives or neighbours is additional to formal care (Koops & Kwekkeboom, 2005). If ageing in place and less admissions to long-term care facilities are the goal, investments in that area are essential. On the one hand, studies in this dissertation illustrate that investments in guaranteed 24 hour care programs and support by antenna professions are worthy. On the other hand, investments in informal care are needed too. Example of good practices are powerful neighbourhoods and active caring communities. An an active caring community is defined as "a community supporting ageing in place; where residents of the community know and help each other; where meeting opportunities are developed; and where individuals and their informal caregivers receive care and support from motivated professionals. This type of 'socially responsible care' refers to high-quality care that remains affordable for the user as well as for society" (Smetcoren et al., 2018, p. 104).

Sometimes, there are boundaries in community care for frail older adults and residential long-term care is needed after all. In the latest report on ageing and health, the concept of ageing in place was already extended to ageing in the right place (Beard et al., 2016; WHO, 2015). Given the importance of well-being in later life, often expressed by older adults themselves, *ageing well in the right place* is the ultimate goal.

5.2 Emphasize the social environment in age-friendly practices

Current aging policy frameworks promote active ageing and social participation to target the challenges of an aging society. This strategy is translated by the World Health Organization via age-friendly cities and communities (AFCCs) (WHO, 2007). Policy has mainly focused on the 8 different topic areas. These topics are very helpful in the development of AFCCs, the findings of this dissertation however suggest that a focus on the social environment can benefit frail older adults. The social environment has largely remained under researched and receives less attention than the physical environment

(Buffel, Phillipson, & Scharf, 2012; Steels, 2015). An important factor for well-being is the presence of local service centers. These service centers are present in Flemish high populated communities. Unfortunately, smaller communities do not yet have these facilities (Van der Gucht, 2016) and mobile service centers are still in their start-up phase (Pareit, 2016).

5.3 Evaluate positive frailty outcomes/ well-being

To date, home-care professionals or the long-term care facilities in the Flemish region of Belgium are regulated according to the Decree of living and care. Regrettably, objective quality indicators only consider following parameters: staffing, personnel training, policy on prices and policy on admissions. When an organization is officially recognized by the government, every six months, an evaluation of quality on care and safety is requested. Again, these indicators only register physical aspects such as bedsores, falls, and medication errors. Not one indicator considers the social or psychological wellbeing of older adults. The Short Well-being Instrument for Older adults that was developed within the D-SCOPE project could be used in the evaluation of well-being in care facilities, after a test-phase.

5.4 Include antenna professionals in the detection of frail older adults

The inclusion of antenna professionals in the detection of frail older adults was only explored within this dissertation. Nonetheless, when municipalities intend to detect frail older adults in their community, local professionals are willing to take up a the role of antenna professional in guiding frail older adults towards appropriate care when needed.

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Chapter 11

Curriculum Vitae

Daan Duppen (born 24 February 1981) graduated as a public health nurse in 2006 at Karel De Grote Hogeschool Antwerpen. After working in geriatric and psychogeriatric wards in national and international hospitals, he got a postgraduate in geriatric nursing in 2010 at VIVES Roeselare (former Katholieke Hogeschool Zuid-West Vlaanderen). While working as a teacher at CVO VSPW Gent, he obtained a Master of Science (MS), management, care and policy in gerontology at the Vrije Universiteit Brussel in 2014. During his master year, he did an internship at the New York Academy of Medicine in the Age-Friendly New York City Department. Since 2015, he works as predoctoral researcher at the Vrije Universiteit Brussel in the Belgian Ageing Studies research group and works within de D-SCOPE project. In his private life, he is married to Kim De Paepe and father of Lin (°2014) and Mona (°2017).

1 PUBLICATIONS IN SCIENTIFIC JOURNALS WITH AN INTERNATIONAL REFEREE SYSTEM

Duppen, D., Lambotte, D., Smetcoren, A.-S., Dierckx, E., Fret, B., Switsers, L., & De Donder, L. (2018). Ageing well in place: kwaliteitsvol thuis wonen met 24-uurszorggarantie. *Verpleegkunde*, *33*(2), 6–13.

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5 GRANTS AND BURSARIES

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Appendix 1: Nederlandstalige Samenvatting (Dutch Summary)

Deze doctoraatstudie focuste zich op 2 grote delen aangaande kwetsbaarheid op latere leeftijd. In deel 1 lag de nadruk op positieve uitkomstmaten in kwetsbaarheidsonderzoek. Deel 2 spitste zich toe op de sociale leefomgeving van ouderen en hoe deze in relatie staat tot kwetsbaarheid.

Deel 1:

Onderzoek naar kwetsbaarheid op latere leeftijd focust zich doorgaans op negatieve uitkomstmaten zoals valfrequentie, hospitalisering, institutionalisering of mortaliteit en niet op welzijn. Nochtans wordt in gerontologisch onderzoek vaak positieve uitkomstmaten gebruikt zoals mentaal welzijn, sociaal functioneren en succesvol, actief of gezond ouder worden. Voor het D-SCOPE project werden verschillende positieve uitkomstmaten van kwetsbaarheid gebruikt. De positieve uitkomstmaten die in de D-SCOPE vragenlijst gebruikt werden zijn uitkomstmaten die door kwetsbare ouderen zelf belangrijk vonden. De eerste studie toonde dit onder andere aan bij een groep kwetsbare ouderen die participeren in een project met 24 uurs zorggarantie aan huis (Zorg24). Deze kwalitatieve studie ging na hoe thuiswonende kwetsbare ouderen hun kwetsbaarheid en hun welbevinden ervaarden en welke factoren ervoor zorgden dat kwetsbare ouderen (n = 18) een positief welbevinden hebben. Kwetsbaarheid werd zeer breed ervaren. Dankzij zorgverleners die hen ondersteunen ervaren zij meer kwaliteit in het leven, zingeving, gevoel van regie over hun leven en betrokken te zijn in de samenleving. Een tweede studie ging na of sociaal kwetsbare ouderen een zinvol leven ervaren. Daarvoor werden 7 dimensies van “need for meaning” gebruikt, naar het werk van de filosoof prof. Peter Derkx. De studie toonde aan dat sociaal kwetsbare ouderen ook een tekort aan de behoefte voor verbondenheid, doel en samenhang ervaren. In een laatste studie werd op basis van bestaande meetschalen van positieve uitkomstmaten een verkorte vragenlijst gemaakt (SWIO).

Deel 2:

In een eerste studie van het tweede deel werd de relatie tussen kwetsbaarheid en de sociale omgeving onderzocht via een systematische literatuurstudie met narratieve analyse. Drie dimensies bleken een relatie te hebben: sociale participatie, subjectieve buurtkenmerken zoals buurtcohesie en socio-economische buurtkarakteristieken. De rol van sociale participatie werd in een volgende kwalitatieve studie verder onderzocht. Resultaten toonden aan dat ouderen ondanks hun kwetsbaarheid op verschillende manieren participeren in de samenleving. Een bijzondere vorm die naar boven kwam uit de narratieven was low-key of laaggradige participatie. Het sociaal netwerk van kwetsbare ouderen is een katalysator voor participatie. Een derde studie onderzocht de relatie tussen multidimensionele kwetsbaarheid en positieve uitkomstmaten, en de modererende rol van zowel de fysieke als sociale leefomgeving. Hier toonden de resultaten aan dat zowel kwetsbare als niet kwetsbare ouderen een hoger welzijn ervaren bij een meer leeftijdsvriendelijke buurt. In de laatste studie werd geëxploreerd hoe professionals met een antenneberoep (zoals bakkers, postbodes, apothekers…) kwetsbare ouderen kunnen detecteren en toe leiden naar zorgorganisaties.

Appendix 2: D-SCOPE (English and Dutch summary)

D-SCOPE (Detection, Support and Care for Older people: Prevention and Empowerment) is an international research project, financed by the Flemish government agency for Innovation by Science and Technology [IWT-140027 Strategisch BasisOnderzoek (SBO)] (2015-2018). The D-SCOPE consortium is a multidisciplinary group composed of researchers from five universities/colleges: Maastricht University, University of Antwerp, University College Ghent, KU Leuven and Vrije Universiteit Brussel. The focus of D-SCOPE is targeted detection of frail older adults in their local environment. The project contributes to the development of new methodologies for the prevention of frailty in older adults, so they can age in their own homes in good quality of life. The D-SCOPE project starts from a multidimensional perspective on frailty, including physical, cognitive, psychological, social and environmental frailty, and focuses on positive outcomes like mastery, life satisfaction and meaning in life. In order to achieve this, the D-SCOPE project was divided in three research phases. In the first phase, risk profiles were determined through data from the Belgian Ageing Studies. In the second phase, balancing factors and life events were explored by means of 121 individual interviews with frail older people. The third and last phase consisted of a randomised study with both an experimental and control group (RCT) in three test municipalities (Ghent, Knokke-Heist and Tienen) among 869 older adults. The D-SCOPE methodology for early detection of frail older adults is hereby tested by previously defined risk profiles for frailty. In addition, strengths frail older people have are explored.

D-SCOPE (Detection, Support and Care for Older people: Prevention and Empowerment) is een internationaal onderzoeksproject, gefinancierd door het Instituut voor Wetenschap en Technologie [IWT-140027 Strategisch BasisOnderzoek (SBO)] (2015-2018). Het D-SCOPE-consortium is multidisciplinair samengesteld en bestaat uit onderzoekers van vijf universiteiten/hogescholen: Universiteit Maastricht, Universiteit Antwerpen, Hogeschool Gent, Katholieke Universiteit Leuven en Vrije Universiteit Brussel. Als onderzoeksfocus staat de gerichte detectie van kwetsbare ouderen in hun lokale omgeving centraal. Het project draagt bij aan het ontwikkelen van een nieuwe methodiek voor de preventie van kwetsbaarheid van ouderen, zodat zij zo lang mogelijk kwaliteitsvol thuis kunnen blijven

wonen. Het D-SCOPE project vertrekt vanuit een multidimensionaal perspectief op kwetsbaarheid (fysieke, cognitieve, psychische, sociale en omgevingskwetsbaarheid) en legt de focus op positieve uitkomstmaten zoals zelfregie, levenstevredenheid en zingeving. Om dit te bereiken werd het D-SCOPE onderzoek opgedeeld in drie fasen. In de eerste fase werden risicoprofielen bepaald op basis van de data van de ouderenbehoefte-onderzoeken. In de tweede fase is door middel van individuele interviews bij 121 kwetsbare ouderen nagegaan wat balancerende factoren en scharniermomenten zijn. De derde en laatste fase betrof een gerandomiseerd onderzoek met zowel een experimentele als controlegroep (RCT) in drie testgemeenten (Gent, Knokke-Heist en Tienen) bij 869 ouderen. Hierbij is de D-SCOPE methodiek rond vroegtijdige detectie van kwetsbare ouderen uitgetest aan de hand van de eerder gedefinieerde risicoprofielen van kwetsbaarheid. Ook wordt getracht sterktes die kwetsbare ouderen hebben verder in kaart te brengen.

Appendix 3: The Comprehensive Frailty Assessment Instrument Plus (CFAI-Plus)

Have the following activities been hampered by your state of health? If so, for how long? (Please tick all appropriate items)

1= Not at all, 2= 3 months or less, 3= More than3 months

- Less demanding activities likecarrying shopping bags
- Walking up a hill or some stairs
- Bending or lifting
- Going for a walk

Considering the last few weeks, to which extent do you agree with the following (please tick)

1= not at all, 2= not more than usual, 3= more than usual, 4= considerably more than usual

- I feel unhappy and depressed
- I feel like I'm losing my selfconfidence
- I feel like I cannot cope with problems
- I feel like I'm under constant pressure
- I feel like I'm not worth anything anymore

To which extent do you agree with the following statements? (please tick all appropriate items)

1= I completely disagree, 2= I disagree,3= I neither agree nor disagree, 4= I agree,5= I completely agree

- I have trouble with remembering things that have happened recently
- I experience difficulties with learning new things in general
- I experience difficulties with handling financial matters, eg, the pension, dealing with the bank
- I have trouble with following a story in a book or on TV
- I experience a general sense of emptiness
- I miss having people around me
- I often feel rejected

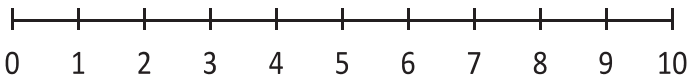
- There are enough people whom I can rely on
- when I am in trouble.I know many people whom I can totally trust
- There are enough people with whom I feel a bond
- My house is in a bad condition/poorly kept
- My house is not very comfortable
- It is difficult to heat my house
- There is insufficient comfort in my house
- I do not like my neighborhood

Suppose you are unable to carry out the activities you usually do in terms of housekeeping for a certain length of time; who would you be able to appeal to?
(Please tick all appropriate items) (More than one answer may be given)

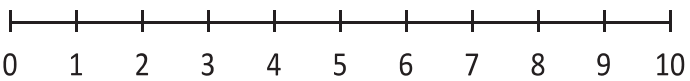
- Partner
- Son
- Daughter-in-law
- Daughter
- Son-in-law
- Grandchild
- Sister or brother (in-law)
- Family
- Neighbours
- Friends

Appendix 4: Numeric rating scales used for the external validation of the SWIO:

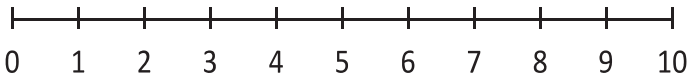
On a scale from 0 to 10, how would you rate your QoL? (O=very bad, 10 = very good



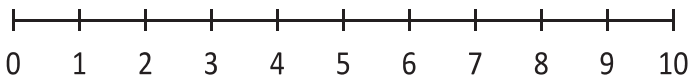
On a scale from 0 to 10, to what extent do you feel that your life is meaningful (worthwhile, useful, having desires), that you are looking or striving for something?



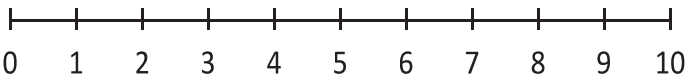
On a scale from 0 to 10, to what extent do you feel in control of what happens in your life?



On a scale from 0 to 10, to what extent you feel part of the society?



On a scale from 0 to 10, to what extent you feel frail?



APPENDIX 5: SHORT WELL-BEING INSTRUMENT FOR OLDER ADULTS (SWIO)

The SWIO can be used to measure well-being in later life. It assesses three subdimensions of well-being, namely **sense of mastery**, **meaning in life** and **life satisfaction** by means of statements. Respondents are asked to give their answer on a five-point Likert scale (totally disagree to totally agree). The SWIO is a validated instrument that uses items derived from three larger scales. For more information on these scales, see the references below.

In order to assess the subdimensions of well-being, please ask to what extent he or she agrees on the following statements. Please cross every item.

1= Totally disagree
2= Disagree
3= Nor agree, nor disagree
4= Agree
5= Totally agree

Sense of mastery

	1	2	3	4	5
1. I can't solve some of the problems I have					
2. I have little control over the things that happen to me					
3. I often feel helpless in dealing with the problems of life					

Meaning in life

	1	2	3	4	5
4. I understand my life's meaning					
5. I have a good sense of what makes my life meaningful					
6. I have discovered a satisfying life purpose					

Life satisfaction

	1	2	3	4	5
7. The conditions of my life are excellent					
8. I am satisfied with my life					
9. So far I have gotten the important things I want in life					

Appendix 6: Search strategy systematic review (chapter 6)

For Web of Science core collection

#6	(#5) *AND* **LANGUAGE:** (English) Indexes=SCI-EXPANDED, SSCI, A&HCI,CPCI-S, CPCI-SSH Timespan=All years
#5	#4 AND #3 AND #2 AND #1
#4	TS=(Frail*)
#3	TS=(elder* OR "later life" OR "older*" OR age* OR ag$ing)
#2	TS=("network" OR "support" OR environment OR "cohesion" OR "capital" OR relation* OR *social)
#1	TI=(health OR frail* OR vulnerab* OR well-being)

For Pubmed

((((("social environment"[MeSH Terms] OR "community networks"[MeSH Terms] OR "social support"[MeSH Terms])))) AND "Frail Elderly"[MeSH Terms]) AND (frail*[Title/Abstract] OR health[Title/Abstract] OR vulner*[Title/Abstract]) AND English[lang])

Ovid Pscychinfo

(health or frail* or vulnerab* or well- being).ti. and frail*.ab. and (network or support or environment or cohesion or capital or relation* or *social/).ab.

Proquest Social Science

(EconLit (1969 - current) ,ERIC (1966 - current) PILOTS: Published International Literature On Traumatic Stress (1871 - current), Social Services Abstracts (1979 - current),

Sociological Abstracts (1952 - current)

S4	ti(health OR frail* OR vulnerab* OR well-being) AND ab(frail*) AND (network OR support OR environment OR cohesion OR capital OR relation* OR *social)
S3	(network OR support OR environment OR cohesion OR capital OR relation* OR *social)
S2	ab(frail*)
	ti(health OR frail* OR vulnerab* OR well-being)

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