WHO CARES?!

A comprehensive study on care and support in community-dwelling older adults. Focus on access, expenditures and follow-up.

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wit-gele kruis VLAANDEREN
VUB VRIJE UNIVERSITEIT BRUSSEL
D-SCOPE detection, support and care for older people: prevention and empowerment

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Who cares?! A comprehensive study on care and support in community-dwelling older adults. Focus on access, expenditures and follow-up.

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Bram Fret, oktober 2018

"Door doorzettingsvermogen bereikt de slak de ark" (Frank Focketyn, In de gloria, 2000)

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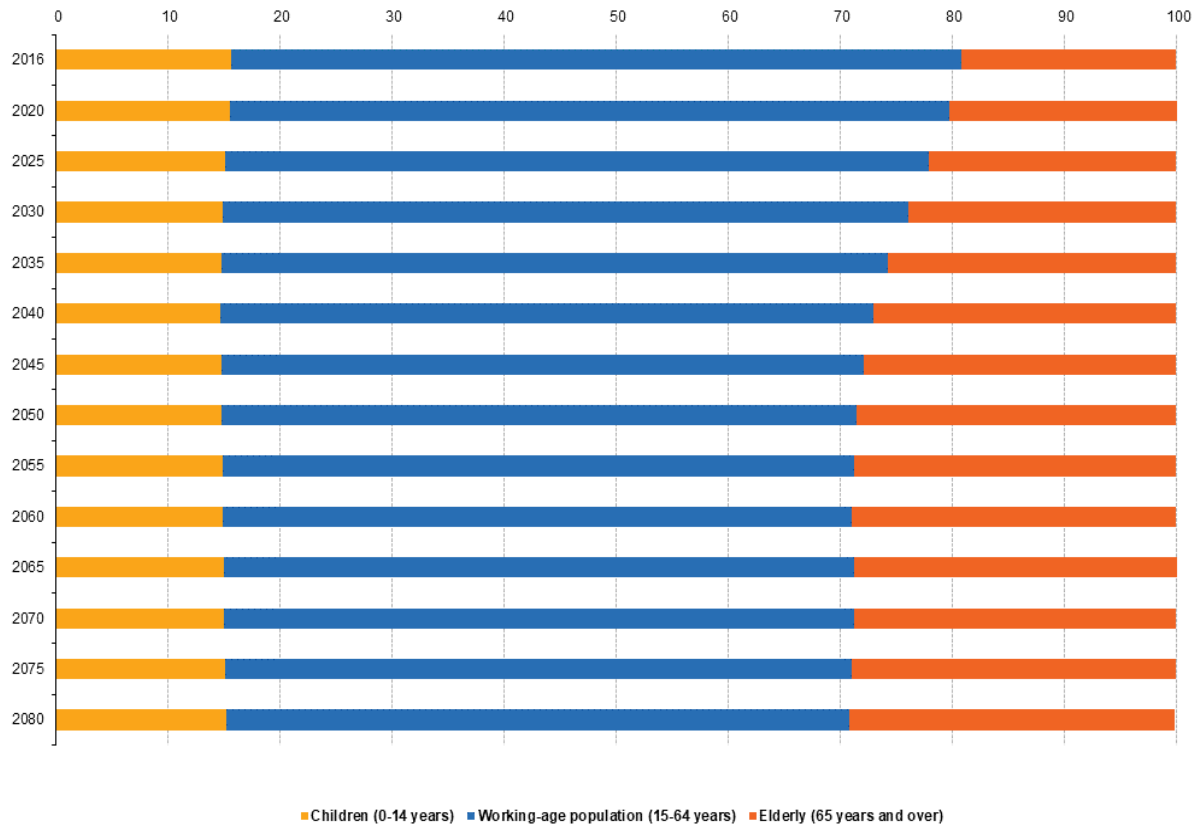
Chapter 1 : General introduction

1.1. The ageing population

This doctoral dissertation focuses on access to care and support for frail community-dwelling older adults in Belgium. The ageing population is one of the greatest social and economic challenges facing the European Union. Projections foresee a growing number and share of older adults (aged 65 years and over), with a particularly rapid increase in the number of very old adults (aged 85 years and over) (Eurostat, 2018).

Figure 1. Population by broad age group, 28 EU member countries, 2016-2080 (source: Eurostat, 2016)



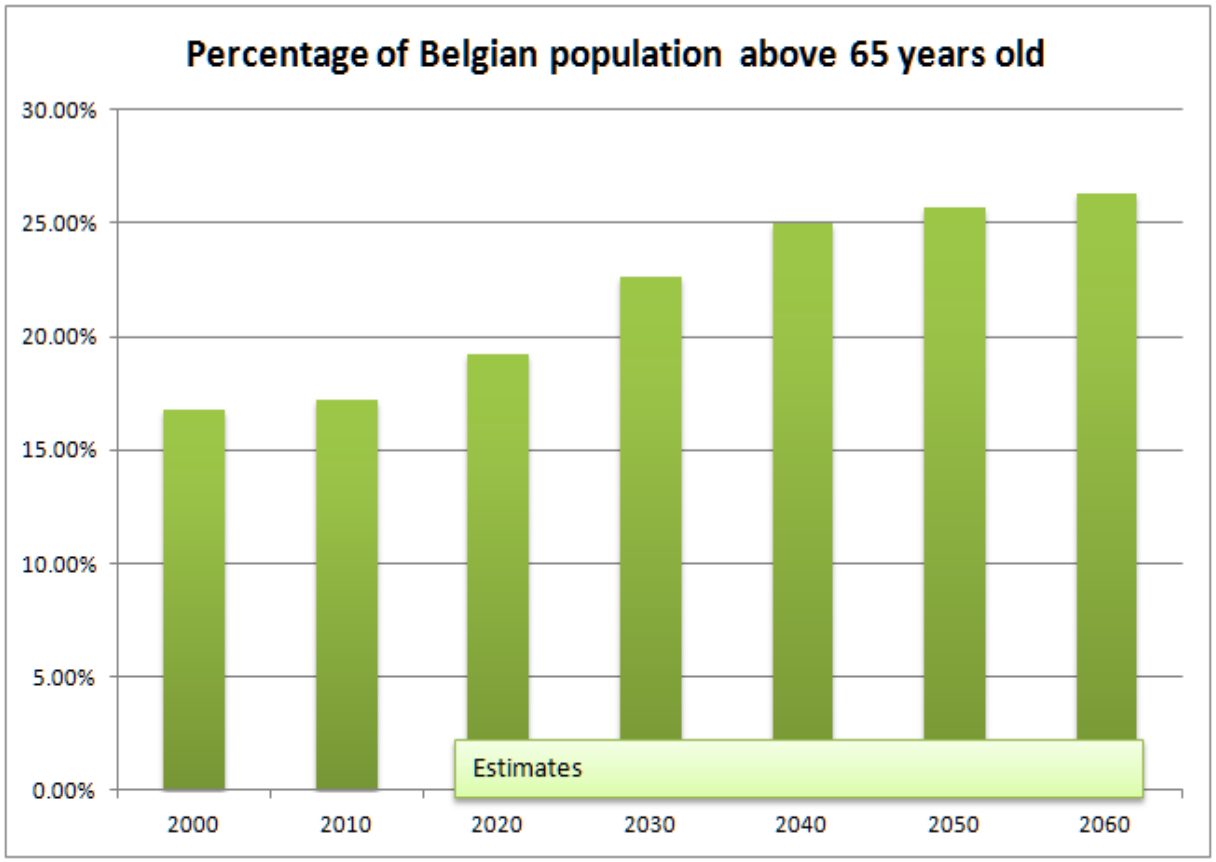
Note: 2016, estimates. 2020-2080: projections.
Source: Eurostat (online data codes: demo_pjanbroad and proj_15ndbims)

These demographic developments are likely to have a considerable impact on different policy areas: different health and care requirements for older adults, but also labour markets, social security and pension systems as well as government finances (Eurostat, 2018).

Belgium is no exception to the trend of ageing: the Belgian population is at the moment counting one person of 67 or older for every four persons between the age of 18 until 66 years old, in 2040 this proportion is projected to be one person of 67 or older for every 2.6 persons between the age of 18 until 66 years old (Vanresse et al., 2017).

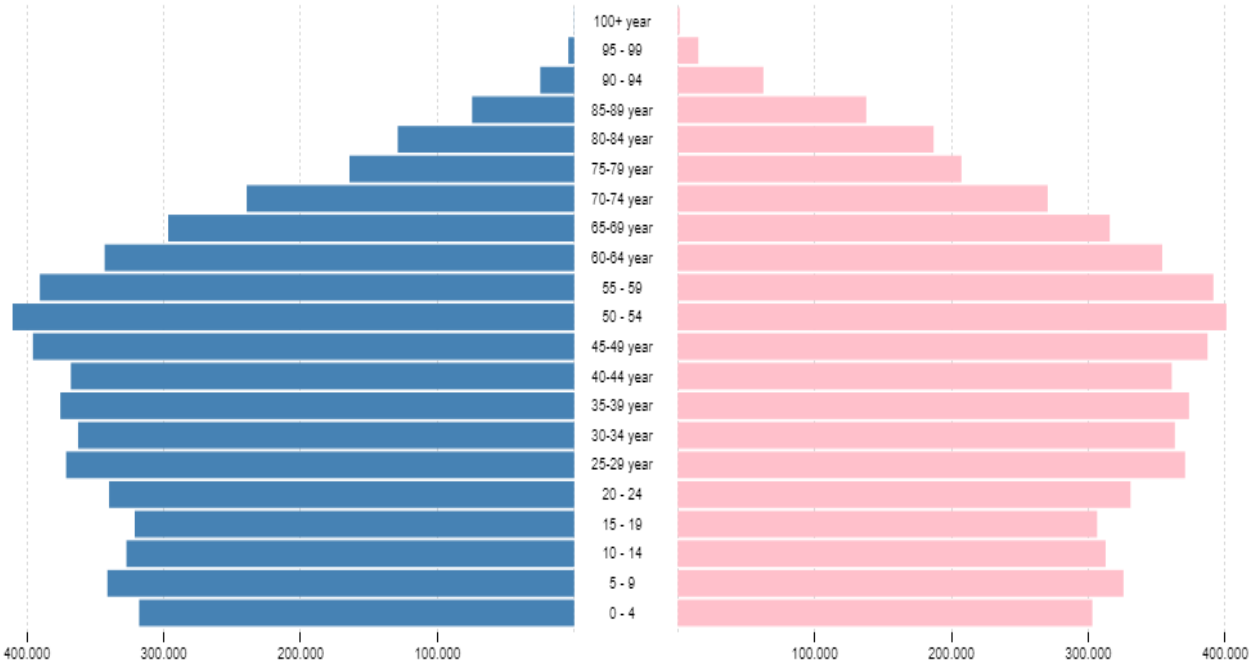
Because the generation of babyboomers is gradually getting older, the ageing process within the Belgian population will increase until 2040 and thereafter stabilise until 2070. The ageing of the Belgian population also has an influence on the types of households: the share of one-person households will increase further (Vandresse et al., 2017). Simultaneously with the ageing population, due to high-quality medical care and better economical living conditions, the total fertility rate in Belgium has dropped from 2.55 children per woman in 1960 to a low of 1.49 in 1985. Continuously, it has recovered quite strongly to 1.83 in 2012, a rise that was largely a result of delayed childbirth (Marx and Schuerman, 2016).

Figure 2. Percentage of Belgian population above 65 years old (source: http://data.gov.be)



The Belgian population has a relatively high life expectancy. Life expectancy at birth in Belgium has increased by over three years since 2000 to reach the age of 81.1 in 2015, half a year more than the EU average (OECD, 2017). A substantial gender gap in life expectancy persists in Belgium, with men living on average nearly five years less than women in 2015. However, no gender gap exists in the number of healthy life years, as women live a larger proportion of their life with some disabilities. At age 65, both women and men in Belgium can expect to live about 11 years free of disability, which is 50% of the remaining years of life for women and 60% for men (OECD, 2017). There are also some inequalities in life expectancy by socio-economic status. At the age of 50, Belgian men with the lowest level of education can expect to live about six years less than those with the highest education level. The gap among women is a bit smaller (about five years) (OECD, 2017).

Figure 3. Population by gender and age structure, Belgium, 2018 (source: https://statbel.fgov.be)



There is a general consensus, also in Belgium, that countries need to be prepared for the ageing population, because demographic changes will challenge healthcare systems all over the world (Paulus et al., 2012).

1.2. Care and support policy in Belgium

Healthcare in Belgium consists of a wide range of services organised at the federal, regional and municipal levels, and is related to health and social service provision (Willemé et al., 2011). Three political and administrative levels operate in the Belgian care system: the Federal government, the Federated governments (regions) and the local governments (provinces and municipalities) (Gerkens and Merkur, 2010). Since the State Reform of 1980, Flanders holds the responsibility for 'person-related matters', such as care and welfare. Nevertheless, the Federal government is still to al large extent responsible for both the financing of healthcare acts as for the healthcare policy. These three mentioned levels have in common that they are mainly funded by taxes (with some out-of-pocket patient contributions). The federal level is mainly responsible for social security, compulsory health insurance, pharmaceutical policy and hospital legislation. This federal government is also in charge for medical professions (general practitioners, home nurses, home healthcare assistants, etc.) whereas the regional authorities are mainly responsible for prevention and support services at home (cleaning aids, family aids, the organisation of meals on wheels, support for housing modifications, etc.) (Gerkens and Merkur, 2010). As these different services (both care and support services) are often simultaneously applied for and used by recipients, they form together the Belgian homecare system and when we speak about 'home care', it implies all these different components. Consequently, in Belgium no clear separation is made between health and social care (in comparison with for example the UK) or no clear separation between care and support services as they often interfere, are complementary to one another.

This broad approach on care and support is followed by the government in new legislation, for example in the new Flemish legislation on primary care (Flemish government, 2018, p. 2) the following definitions concerning 'care and support'[1] are given:

"care and support: every activity or series of activities in the frame of health- and social care policies;

care and support plan: a working instrument in which, after a clarification or indication process, the care and support goals and the agreements about the planned care and support for the person with a care and support request are included, and which is accessible to the persons care team;

[1] In the new 'Preliminary draft of decree concerning the organisation of primary care, the regional care platforms and the support of the primary care providers' (Voorontwerp Eerstelijnsdecreet) that has been approved by the Flemish Government in September 2018, the Dutch terms 'zorg en ondersteuning', 'zorg- en ondersteuningsplan', 'zorg- en ondersteuningsdoel' and 'zorg- en ondersteuningsvraag' are used.

care and support goal: a goal formulated by the person with a care and support request, his representative or informal caregiver and his care providers regarding the desired care, facing the life goals and the quality of life that the person with a care and support need wants to achieve;

care and support request: the need for care and support that a person or his environment feels or that is objectively determined"

Within this descriptions, care and support clearly goes beyond solely medical services. Moreover, perceived access barriers by Belgian users are often not related to a specific system or political level or type of service but concern the broader 'care and support' field. This was also a conclusion of a scientific committee that evaluated pilot projects on care and support for frail community-dwelling older adults in Belgium (i.e. Protocol 3 projects, chronical care projects, pilot project on 'integrated broad access').

Belgian older adults use both formal and informal care rather frequently compared with other European countries (European Commission and Economic Policy Committee, 2016). Data from the 2004 Survey of Health Ageing and Retirement (SHARE) indicate that the proportion of users of professional nursing care and professional homecare is among the highest in Europe (13.4 and 16.6 % respectively) (Geerts, 2009). The Belgian elderly care field comprises homecare and community services, short-term and long-term residential care and hospital care. Long-term residential care includes service flats, residential homes for the elderly and nursing homes. (Gerkens and Merkur, 2010). As in other European countries, in Belgium the majority of older adults prefer to live at home as long as possible (Smetcoren, 2016). This has led to the development of a wide range of home assistance, welfare and personal care services as well as short-term or temporary care facilities (Willemé, 2010).

1.2.1. The Belgian national health insurance system

Healthcare in Belgium is nationally organised. Everyone living and/or working in Belgium can be entitled to subsidised Belgian healthcare by means of the compulsory health insurance system. This compulsory health insurance is managed by the National Institute for Health and Disability Insurance (NIHDI-RIZIV-INAMI), which allocates a prospective budget to the health insurance funds to finance the healthcare costs of their members. All individuals entitled to health insurance must join or register with a health insurance fund: either one of the six national associations of health insurance funds, including the Health Insurance Fund of the Belgian railway company, or a regional service of the public Auxiliary Fund for Sickness and Disability Insurance. Private profit-making health insurance companies

account for only a small part of the non-compulsory health insurance market. In the past, health insurance funds received the budget they needed to reimburse their members, but since 1995 they have been held financially accountable for a proportion (25%) of any discrepancy between their actual spending and their budget (Gerkens and Merkur, 2010).

The Belgian health system is based on the principle of social insurance, characterised by horizontal solidarity (between healthy and sick people) and vertical solidarity (based to a large extent on the labor incomes) and without risk selection. Financing is based mostly on proportional social security contributions related to taxable income and, to a lesser extent, on progressive direct taxation, and a growing area of alternative financing related to the consumption of goods and services (mainly value added tax) (Gerkens and Merkur, 2010).

1.2.2. The sixth Reform of the State

Since the adoption of the 1831 Constitution, six constitutional revisions have progressively transformed Belgium from a unitary into a Federal state, in particular since 1970. The last reform, started in 2011 and operational since 2014, further strengthened the defederalisation of the country. Belgium has three tiers of subnational governments: six Federated states, including three regional governments (Flanders, Wallonia and the Brussels Capital-Region) and three community governments (Flemish, German, and French Speaking Communities) which overlap territorially; 10 provinces; and 589 municipalities which are governed by regional legislation. Flanders and Wallonia regions have started reforming the provincial and municipal levels in their respective territories. In Flanders, the government is engaged in voluntary municipal mergers and the 'downsizing of the provinces' which will focus more on 'territory-related powers', losing the 'person-related powers' as well as some taxing powers. The Walloon Government aims at 'optimising' the role of the provinces by developing 'supra-municipalities' (OECD, 2015).

The main change in healthcare policy legislated in the recent years concerns the devolution of responsibilities (and shifts in associated budgets) for a number of healthcare tasks from the Federal to the regional level (Flanders, Wallonia and Brussels) as a consequence of the sixth Reform of the State. The reform was signed into law on the 31st of January 2014 and became effective on the 1st of July 2014. The total budget shift from the Federal to the regional level was approximately 3.4 billion euros in 2015, almost 12% (400 million euros) of which were (acute) healthcare expenditures (European Commission and Economic Policy Committee, 2016). Some responsibilities were entirely transferred to the regions, while others are more fragmented.

The sixth Reform of the State has in particular given new competences to the Federated states in the field of long-term care and elderly care. This was accompanied by a transfer of significant budgets and financing from the national health insurance to the Federated states (Vandeurzen, 2015). With the sixth Reform of the State of 2014, additional competencies have been transferred to the Federated states, including since 2014 family allowances, elderly care, several aspects of healthcare, hospitals, justice homes, etc.

However, coordination with federal policy remains necessary. After all, Flanders is not competent for the entire elderly care field. Home nursing, general practice, various other health professions (e.g. dietetics, physiotherapy, speech therapy, pharmaceutical care, etc.) and geriatric hospital care (geriatric care programs) are financed by the health insurance and have therefore remained a Federal competence.

Since the sixth Reform of the State, the Welfare, Public Health and Family Department of the Flemish Community has become a more important pillar of the Flemish policy: the department manages a budget of 11 billion euros (cf. the entire Flemish budget is around 39 billion euros) (VVSG, 2014).

1.2.3. 'Socialisation of care' and 'ageing in place'

The broad field of care and support in Belgium has been in full transition in recent years. *'Socialisation of care'* is a term that has been very common in care policy during the last years. This term has its origins in the shift from 'institutionalised care' to a 'de-institutionalisation of care', already around the 1980's of last century (Boekholdt, 2011). Socialisation of care started in mental health care, where care for psychiatric patients was increasingly provided outside the walls of an institution by professionals visiting at the home of the clients. This trend continued with other care recipients, including people with disabilities and older adults.

The proportion of older adults staying in residential care facilities has decreased in recent years. Consequently, the care dependency of older adults staying in residential care has increased strongly from around 30% in 2010 to almost 50% in 2015 (Flemish Government, 2017d). The largest group of older adults live independently at home up to a very old age or with a considerable need of care.

A very large group of older adults wish to become older in the familiar environment (Löfqvist et al., 2013; Smetcoren, 2016). In the international literature the term 'ageing in place' is used to describe the trend in which older people want to live at home as long as possible. In addition to the wishes of older adults themselves, this is also a policy ideal which receives the necessary attention both within

the European agenda and globally. For example, 'ageing in place' is defined by the World Health Organisation as: "Meeting the desire and the ability of people to continue living independently for as long as possible in their current home or an adapted living by offering services and assistance" (WHO, 2004, p.9). In recent years, the focus within policy development has moved more and more to 'ageing *well* in place'.

Throughout the years, the concept of 'socialisation of care' has evoluated from 'care *in* the community' to 'care *through* the community' (De Donder er al., 2017), with a strong focus on self-care, informal care and care by volunteers. Socialisation is not solely about de-institutionalisation, but assumes that care is provided in a familiar environment, by people who are close to the person with care or support needs. In this context, the care process is then no longer only a responsibility of professionals, but society and individual citizens are also given an important role (Koops & Kwekkeboom, 2005; Linders, 2007).

The Flemish Government is currently implementing the socialisation principle of care in its policy. It has become a conscious policy choice. Several Flemish policy texts emphasise and recognise the importance of volunteering and informal care. The Flemish Informal Care Plan (2016-2020, p.1) states: "Good care is part of the daily social life of people. This care is also shaped by the efforts of many informal carers, they give meaning and color to the life of the care recipient. Professional care supports this participation and involvement." Minister Vandeurzen regularly uses the World Health Organisation model on personal and integrated care in his policy texts. This model positions the informal carer, the family, volunteers and the neighborhood as the first protective circle around the central person with care needs. Research indicates that the percentage of people in Flanders that is taking up informal care has decreased from 38% to 26% between 2011 and 2014. However, within this group of informal carers the burden increased from 18% to 23% in the same period (Vanderleyden and Moons, 2015). This is why the high expectancies society has towards socialisation of care have to be adapted to the informal care network.

This is in line with the recently developed model of 'community-centered care'. 'Community-centered care' is a future model for the organisation of care, support and care provision, in order to keep care and support accessible, available and affordable for everyone. This model offers opportunities for increasing the quality of life and reducing the costs of care and care provision. It aims at a coherent and neighborhood-oriented approach to living, care and welfare, with the client in a central role. The goal of 'community centered care' is to build a permanent collaboration between the various partners (formal and informal) (Bekaert et al., 2016).

1.3. A positive approach of frail older adults

Frailty is a common phenomenon in community-dwelling older adults that is often used in research as a (clinical) phenotype (Fried et al., 2001) or an accumulation of health deficits (Rockwood et al., 1994; Etman et al., 2012). Being a major health condition associated with ageing, the concept of frailty is almost universally accepted, but the operational definition remains controversial (Buckinx et al., 2015). Frailty is often regarded as a clinical syndrome that carries an increased risk for poor health outcomes including falls, incident disability, hospitalisation and mortality (Xue, 2012). This is what is defined as the clinical phenotype by Fried and colleagues, a well-defined syndrome with a biological basis (Fried et al., 2001). More recently, multidimensional approaches have defined frailty as 'a dynamic state that affects an individual who experiences losses in one or more domains (physical, psychological, social, and more recently, also environmental)' (De Witte et al., 2013; Gobbens, et al., 2010; Rockwood, et al., 2006). Also, different researchers point to the necessity to operationalise frailty as a multidimensional and dynamic concept that considers the complex interplay of physical, cognitive, psychological, social and environmental factors (Bergman et al, 2007; Armstrong et al., 2010; De Witte et al., 2013). The word frailty has a stigma attached pointing towards losses and decline. Although, frailty not solely has negative consequences in daily life, especially when the right care and support is present. This suggests that besides measuring the deficits of frailty, there is also a need to consider the strengths and resources of older adults (Buntinx et al., 2004). This is in line with Baltes and Smith (2003) who suggest the recognition of two faces of human ageing, including both the gains and the losses. Such gains might also be seen in the context of losses, as older adults may unfold unexpected substitute skills, collaborative relationships or creative strategies to overcome limitations (Hansson et al., 2001). In addition, people that have been classified by others as frail, do not always identify themselves as such (Grenier, 2007).

1.4. Access to care and support

In general, when looking at access to care and support, Belgium is often quoted as one of the best examples. This was reconfirmed by a recent report (from 2017) of the Health Consumer Powerhouse concluding that Belgium has Europe's fourth best healthcare system when analysing on 48 indicators, considering areas such as patient rights and information, access to care, treatment outcomes, range and reach of services, prevention and use of pharmaceuticals. In terms of 'accessibility' (i.e. waiting times for treatment), Belgium even obtained the maximum score (Björnberg, 2017).

Nevertheless, several challenges in terms of access to care and support in Belgium remain. Although Belgium is considered to have an efficient and accessible health system, not everyone is able or literate to find the appropriate services. Research indicates that 6.4% of older adults in Belgium report care shortages (De Witte et al., 2010). Also, the Organisation for Economic Cooperation and Development (OECD) (2016) states that Belgium shows large inequalities: low-income people more often forgo health examinations due to costs, travelling distance or waiting times, compared to high-income people. Despite universal coverage, on average 8% of Belgian households declared in 2013 that they had to postpone healthcare for financial reasons (e.g. medical care, surgery, dental care, prescribed medicines, mental healthcare, eyeglasses or contact lenses).

Already more than 30 years ago, Penchansky and Thomas (1981, p. 1) developed an influential framework wherein access is described as 'a general concept that summarises a set of more specific dimensions describing the fit between the patient and the healthcare system'. Within this framework, five A's (affordability; availability; accessibility; adequacy (or accommodation) and acceptability) to measure access to care were developed. Recently, Saurman (2016) has re-evaluated, improved and extended Penchansky and Thomas' framework to the actual context and added a sixth A, namely 'awareness'. The framework of Penchansky and Thomas is still commonly used also in a broader context of access to services (United Nations Educational, Scientific and Cultural Organisation, 2013), for example to discover access barriers to healthy food (Usher, 2015; Zhang, 2017), access to energy security (Cherp and Jewell, 2014) and access to education (Lee, 2016); although it has never been used in a context of older adults and homecare. This lack of evidence on access to care and support for community-dwelling older adults can be defined as a gap in existing research.

Furthermore, even when older adults are able to access care and support services, avoiding and reducing drop-out from care remains a challenge. Although there has been a considerable amount of policy attention and funding for researchers and healthcare providers concerning prevention programs within community-dwelling older adults in order to evaluate interventions which may reduce or delay institutionalisation, there has been limited attention for follow-up initiatives after an intervention or a preventive home visit (Cutchin et al., 2009; Mayo-Wilson et al., 2014; Mello et al., 2012; Van Durme et al., 2015). This is also an aspect that could use further exploration.

1.5. Research questions and dissertation structure

As explained above, frailty within community-dwelling older adults does not necessarily have negative consequences in daily life, especially when high-quality tailored care and support services are present. However, older adults do not always find this appropriate care and support and are often left undetected (De Witte et al., 2010; Willemé, 2010). The present doctoral dissertation aims to explore which are the conditions to organise and provide access to this high-quality care and support for (frail) community-dwelling older adults.

The following research questions where explored:

Research question 1

Which socio-demographic and socio-economic characteristics within community-dwelling adults can be associated with different types of care use?

Research question 2

What are the main barriers frail, community-dwelling older adults experience in accessing formal care and support (services) and how can access be improved?

Research question 3

What are the biggest expenditures of community-dwelling older adults and which costs are important in causing financial difficulties?

Research question 4

What can be the added value of a follow-up process after preventive home visits within community-dwelling older adults to increase *sustainable* access to care and support? And how can this follow-up be organised?

In order to give an answer to the formulated research questions, the doctoral dissertation consists of four studies:

1. The first study investigates which different patterns of formal and informal care use that can be detected among Belgian community-dwelling older adults on the one hand and on the other hand what the relation is between socio-demographic/socio-economic characteristics, health needs and these identified patterns of care use;

2. The second study describes the barriers frail, community-dwelling older adults experience to access formal care and support services;
3. The third study describes all income and expenditures of older adults with care needs living at home in order to evaluate the affordability of care and support for community-dwelling older adults;
4. The fourth study reports on the added value of monthly telephonic follow-up (for older adults, (in)formal caregivers and society) after preventive home visits within a detection and prevention program for frail community-dwelling older adults.

1.6. The D-SCOPE project

The present doctoral dissertation is written in the frame of the D-SCOPE project. The D-SCOPE project is a four-year interuniversity, multidisciplinary research project (2015-2018) that investigates strategies for proactive detection of potentially frail, community-dwelling older adults, in order to guide them towards adequate support and/or care with a focus on empowerment.

The D-SCOPE research team consists of neurologists specialised in dementia, psychologists specialised in neuropsychology and dementia, adult educational scientists specialised in social gerontology, general practitioners specialised in frailty in later life and social gerontologists specialised in public health. In the frame of the D-SCOPE project, seven doctoral dissertations were written. The present doctoral dissertation is one of them.

The D-SCOPE acronym

Detection: Proactive detection and prevention of frailty (from a physical, psychological, social, environmental, and cognitive perspective)

Support: High-quality support, tailored to the older individual

Care: High-quality care, tailored to the older individual

Older people: (Independent) home-dwelling older people

Prevention: Primary, secondary and tertiary prevention of frailty

Empowerment: Supporting the autonomy and self-determination of older people, their informal carers and social environment

The D-SCOPE-project consisted of three research phases: 1) development of multidimensional frailty risk profiles; 2) identification of balancing factors and positive outcomes; and 3) development of a frailty balance assessment instrument and intervention.

The first research phase of the D-SCOPE project consisted of the development risk profiles for multidimensional frailty, which included age, gender, marital status, level of education, household income, whether the respondent had moved in the previous ten years and country of birth (Dury et al., 2016).

The second research phase aimed to examine how frail, older adults perceive their frailty, quality of life, care and support, meaning in life, and mastery (as in mastering their own situation and being in control of the situation they live in). It also aimed to identify balancing factors that might influence the relation between frailty and positive outcome variables. Another objective was to explore which life changes and turning points older people experience and how these affect their frailty, quality of life, care and support, meaning in life, and mastery (Dury et al., 2018).

Within the third research phase, a D-SCOPE detection and prevention program was evaluated by means of a Randomised Controlled Trial (RCT). The RCT was conducted in three municipalities in Flanders (Belgium): Knokke-Heist, Ghent and Tienen. Study participants were community-dwelling older adults aged 60 years and over. The RCT compared usual care with an intervention that included a preventive home visit from a professional caregiver, tailored care and support when needed, and regular follow-up telephone calls (Lambotte et al., 2018).

1.7. Description of datasets used for the dissertation

The following table provides an overview of the four research articles that are being part of the dissertation, the study population that was investigated and the origin of the datasets used within the research.

Table 1. Overview of research articles and origin of the data

Title	Study population	Origin of the data	Role of the researcher within the project	Journal	Status of the article
1. Socio-demographic, socio-economic and health need differences between types of care use in community-dwelling older adults	12,481 community-dwelling older adults who received any type of care or assistance, plus older people who were shown to be in need of care and assistance but did not receive it.	The data used in the article is cross-sectional and originates from the Belgian Ageing Studies (BAS), a research project that explores the needs and aspects of quality of life among community-dwelling older adults (i.e. informal care, formal care, frailty, well-being, social participation, housing, etc.) by using a standardised survey.	The researcher is a member of the Belgian Ageing research team and conducted a secondary exploration on the data.	International Journal of Care and Caring	Published
2. Access to care of frail community-dwelling older adults in Belgium: a qualitative study	22 community-dwelling older adults who were medium to highly frail according to the CFAI-plus and reported to be in need of care and support at the moment of the interview.	The general aim of the 2nd phase of the D-SCOPE-research, where this article is taking part in, was to gain information concerning the experiences and meaning of older people on frailty and their possibility to age in place. The overall data collection within the 2nd phase of the D-SCOPE research comprised data of 121 community-dwelling older adults.	The researcher is a member of the D-SCOPE research team and participated in the data collection within the 2nd phase of the D-SCOPE research.	Primary Health Care Research & Development	Accepted

3. Exploring the cost of 'ageing in place': expenditures of community-dwelling older adults in Belgium	173 community-dwelling older adults that collected all actual income and costs during the period of one month.	Participants were selected within the members of an insurance company, within the 'Active Caring Community' project and by 3rd bachelor university students 'Adult Educational Sciences'.	The researcher took part in the steering committee established for the study.	Ageing International	Published
4. Preventive home visits among frail community-dwelling older adults. The added value of follow-up telephone calls	149 community-dwelling older adults that received telephonic follow-up / focus groups with 18 community-dwelling older adults, 15 informal caregivers and 11 professional caregivers.	The general aim of the 3rd phase of the D-SCOPE research consisted of an RCT that compared usual care with an intervention that included a preventive home visit from a professional caregiver, tailored care and support when needed, and regular follow-up telephone calls.	The researcher is a member of the D-SCOPE research team and participated in the data collection within the 3rd phase of the D-SCOPE research.		Ready to submit

References

Armstrong, J.J., Stolee, P., Hirdes, JP. and Poss, J.W. (2010). Examining three frailty conceptualizations in their ability to predict negative outcomes for home-care clients. *Age and ageing*, *39*(6), 755-58.

Baltes, P.B. and Smith, J. (2003). New frontiers in the future of aging: From successful aging of the young old to the dilemmas of the fourth age. *Gerontology*, *49*(2), 123-35.

Bekaert, A., Denys, B., De Muynck, J., De Vriendt, T., Foriers, L., Moons, S., Peeters, T., Plas, G., Sablon, W., Teugels, H., Theys, F., Tomsin, W., Verhoeven, I., Vervaet, C. and Verté, D. (2016). *Buurtgerichte Zorg. De actief zorgzame buurt als toekomstmodel voor Vlaanderen en Brussel,* Brussel: VVDC & Kenniscentrum Woonzorg Brussel, 2016.

Bergman, H., Ferrucci, L., Guralnik, J., Hogan, D.B., Hummel, S., Karunananthan, S. and Wolfson, C. (2007). Frailty: an emerging research and clinical paradigm - issues and controversies. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *62*(7), 731-37.

Björnberg, A. (2017). Euro Health Consumer Index 2016. Report. Marseillan: Health Consumer Powerhouse.

Boekholdt, M. (2011). Ouderenzorg en gemeenschapsvorming. In C. Smits, M. Hettinga and A. Mulder (Eds.), *Communities van en voor ouderen: een wereld van kansen* (pp.8-20). Den Haag: Boom Uitgevers.

Bronselaer, J., Vandezande, V., Vanden Boer, L. and Demeyer, B. (2016). Sporen naar duurzame mantelzorg: hoe perspectief bieden aan mantelzorgers. Brussel: Departement Welzijn, Volksgezondheid en Gezin.

Buntinx, F., Paquay, L., Fontaine, O., Ylieff, M. and De Lepeleire, J. (2004). Options For a new procedure for determining care needs in Belgium: an initial exploration. *Archives of public health*, *62*, 173-84.

Buckinx, F., Rolland, Y., Reginster, J.Y., Ricour, C., Petermans, J. and Bruyère, O. (2015). Burden of frailty in the elderly population: perspectives for a public health challenge. *Archives of Public Health*, *73*(1), 19.

Cherp, A. and Jewell, J. (2014). The concept of energy security: Beyond the four As. *Energy Policy*, *75*, 415-21.

Cutchin, M.P., Coppola, S., Talley, V., Svihula, J., Catellier, D. and Shank, K.H. (2009). Feasibility and effects of preventive home visits for at-risk older people: design of a randomized controlled trial. *BMC geriatrics, 9*(1), 54.

De Donder, L., Smetcoren, A.-S., Dury, S., Van Regenmortel, S., Lambotte, D., Duppen, D., Fret, B., Brosens, D., De Witte, N. and Verté, D. (2017). Zorginnovatie in Vlaamse proeftuinen: Onderzoek naar Actief Zorgzame Buurten in Brussel en Antwerpen. Brussel: Belgian Ageing Studies.

De Witte, N., Buffel, T., De Donder, L,. Dury, S. and Verté, D. (2010). Care shortages in later life: the role of individual and contextual variables in Flanders, Belgium. *International Journal of Social Sciences and Humanity Studies*, *2*(1), 111-18.

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

Dury, S., De Roeck, E., Duppen, D., Fret, B., Hoeyberghs, L., Lambotte, D., Van der Elst, M., van der Vorst, A., Schols, J., Kempen, G., Rixt Zijlstra, G., De Lepeleire, J., Schoenmakers, B., Kardol, T., De Witte, N., Verté, D., De Donder, L., De Deyn, P., Engelborghs, S., Smetcoren, A. and Dierckx, E. (2016). Identifying frailty risk profiles of home-dwelling older people: focus on sociodemographic and socioeconomic characteristics. *Aging & Mental Health, 21*(10), 1031-103.

Dury, S., Dierckx, E., van der Vorst, A., Van der Elst, M., Fret, B., Duppen, D., Hoeyberghs, L., De Roeck, E., Lambotte, D.F., Smetcoren, A-S., Schols, J.M.F.A., K, Kempen, G.I.J.M., Zijlstra, G.A.R., De Lepeleire, J., Schoenmakers, B., Verte, D., De Witte, N., Kardol, MJM, De Deyn, P.P., Engelborghs, S. and De Donder, L. (2018). Detecting frail, older adults and identifying their strengths: results of a mixedmethods study. *BMC Public Health*, *18*(1), 191.

Etman, A., Burdorf, A., Van der Cammen, T, Mackenbach, J.P. and Van Lenthe, F.J. (2012). Socio-demographic determinants of worsening in frailty among community-dwelling older people in 11 European countries. *J epidemiol community health*, *66*(12), 1116-121.

European Commission and Economic Policy Committee (2016). Joint report on health care and long-term care systems and fiscal sustainability https://ec.europa.eu/info/sites/info/files/file_import/joint-report_be_en_2.pdf Accessed 23 September 2018.

Eurostat (2016). People in the EU – population projections. https://ec.europa.eu/eurostat/statistics-explained/index.php/People_in_the_EU_-_population_projections. Accessed 12 September 2018.

Eurostat (2018). People in the EU - statistics on an ageing society. https://ec.europa.eu/eurostat/statistics-explained/index.php/People_in_the_EU_-_statistics_on_an_ageing_society. Accessed 11 September 2018.

Flemish Government (2017a). Close care in a warm Flanders. Flemish Informal Care Plan (2016-2020). Flemish Government: Brussels.

Flemish Government (2017d). Primary care conference 2017. Flemish Government: Brussels.

Flemish Government (2018). Preliminary draft of decree concerning the organization of primary care, the regional care platforms and the support of the primary care providers. Flemish Government: Brussels.

Fried, L.P., Tangen, C.M., Walston J., Newman, A.B., Hirsch, C;., Gottdiener, J., Seeman, T., Tracy, R, Kop, W.J. and McBurnie, M.A. (2001). Frailty in older adults. Evidence for a Phenotype. *The Journals of Gerontology: Series A, 56*(3), 146-56.

Gerkens, S. and Merkur, S. (2010). Belgium: Health system review. *Health systems in transition*, *12*(5), 1-266.

Geerts, J. (2009). Gebruik van formele en informele zorg door ouderen: Vlaanderen/België in Europees vergelijkend perspectief. In B. Cantillon (Ed.), *Ouderen in Vlaanderen en Europa: tussen vermogen en afhankelijkheid* (pp. 155-189). Leuven: Acco.

Gobbens, R.J., Luijkx, K.G., Wijnen-Sponselee, M.T. and Schols, J.M. (2010). Toward a conceptual definition of frail community dwelling older people. *Nursing outlook*, *58*(2), 76-86

Grenier, A. (2007). Constructions of frailty in the English language, care practice and the lived experience. *Ageing & Society*, *27*(3), 425-45.

Hansson, R.O., Robson, S.M. and Limas, M.J. (2001). Stress and coping among older workers. *Work*, *17*(3), 247-56.

Koops, H. and Kwekkeboom, M.H. (2005). Vermaatschappelijking in de zorg. Den Haag: Sociaal en cultureel planbureau.

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

Lee, J. (2016). Paying for School Choice: Availability Differences among Local Education Markets. *International Journal of Education Policy and Leadership*, 1*1*(5), n5.

Linders, L. (2007). Niet de sterkste schouders. *Sociale interventie. 16*(2), 13-24.

Löfqvist, C., Granbom, M., Himmelsbach, I., Iwarsson, S., Oswald, F. and Haak, M. (2013). Voices on relocation and aging in place in very old age - a complex and ambivalent matter. *The Gerontologist*, *53*(6), 919-27.

Marx, I. and Schuerman, N. (2016). Belgium, or how inertia can have unexpected benefits in times of crisis. In K. Shubert, P. de Villota & J. Kuhlmann (Eds.). *Challenges to European Welfare Systems* (pp. 37-57). New York: Springer International Publishing.

Mayo-Wilson, E., Grant, S., Burton, J., Parsons, A., Underhill, K. and Montgomery, P. (2014). Preventive home visits for mortality, morbidity, and institutionalization in older adults: a systematic review and meta-analysis. *PloS one*, *9*(3), 1-13.

Mello, J.D.A., Van Durme, T., Macq, J. and Declercq, A. (2012). Interventions to delay institutionalization of frail older persons: design of a longitudinal study in the home care setting. *BMC Public Health*, *12*(1), 615.

OECD (Organisation for Economic Co-operation and Development) (2015). Belgium. Federal Country. https://www.oecd.org/regional/regional-policy/profile-Belgium.pdf. Accessed 24 September 2018.

OECD (2016). Health policy in Belgium. http://www.oecd.org/belgium/Health-Policy-in-Belgium-February2016.pdf. Accessed 1 October 2018.

OECD (2017). *Belgium: Country Health Profile 2017*, State of Health in the EU, OECD Publishing, Paris: European Observatory on Health Systems and Policies.

Paulus, D., Van den Heede, K. and Mertens, R. (2012). *Position paper: Organisatie van zorg voor chronisch zieken in België.* Health Services Research (HSR). Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE).

Penchansky, R. and Thomas, J. (1981). The Concept of Access: definition and relationship to consumer satisfaction. *Medical Care*, *19*(2), 127-40.

Rockwood, K. and Mitnitski, A. (2007). Frailty in relation to the accumulation of deficits. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *62*(7), 722-27.

Saurman, E. (2016). Improving access: modifying Penchansky and Thomas's Theory of Access. *Journal of Health Services Research & Policy*, *21*(1), 36-39.

Smetcoren, A. (2016). I'm not leaving!? Critical perspectives on 'ageing in place'. (Published doctoral dissertation Vrije Universiteit Brussel). Brussels: University Press.

United Nations Educational, Scientific and Cultural Organisation (UNESCO) (2013). Opening new avenues for empowerment: ICTs to access information and knowledge for persons with disabilities. http://unesdoc.unesco.org/images/0021/002197/219767e.pdf. Accessed 1 October 2018.

Usher, K.M. (2015). Valuing all knowledges through an expanded definition of access. *Journal of Agriculture, Food Systems, and Community Development*, *5*(4), 109-14.

Vanderleyden, L. and Moons, D. (2015). Informele zorg in Vlaanderen opnieuw onderzocht. Brussel: Studiedienst van de Vlaamse Regering.

Vandeurzen, J. (2015). The Flemish Social Protection: a massive exercise in devolution for the coming five years. Belgium: Leuven.

Vandresse, M., Duyck, J. and Paul, JM. (2017). Demografische vooruitzichten 2016-2060. Bevolking en huishoudens, Brussel: Federaal Planbureau and Statbel.

Van Durme, T., Schmitz, O., Cès, S., Anthierens, S., Maggi, P., Delye, S., De Almeida Mello J., Declercq, A., Macq, J., Remmen, R. and Aujoulat, I. (2015). A comprehensive grid to evaluate case management's expected effectiveness for community-dwelling frail older people: results from a multiple, embedded case study. *BMC Geriatric*s, *15*(1), 67.

VVSG (Vereniging Vlaamse Steden en Gemeenten) (2014). Ouderenzorg en de staatshervorming. http://www.vvsg.be/welzijnsvoorzieningen/woonzorg/Documents/Zesde%20staatshervorming/2014Lokaal06%20-%20Ouderenzorg%20en%20de%20staatshervorming.pdf. Accessed 24 September 2018.

WHO (World Health Organisation) (2004). A Glossary of Terms for Community Health Care and Services for Older Adults. http://www.who.int/kobe_centre/ageing/ahp_vol5_glossary.pdf. Accessed 24 September 2018.

Willemé, P., Geerts, J., Cantillon, B. and Mussche, N. (2011). Long-Term Care Financing in Belgium. In J. Costa-Font and C. Courbage (Eds.), Financing Long-Term Care in Europe (pps 300-321). London: Palgrave Macmillan UK.

Xue, QL. (2011). The frailty syndrome: definition and natural history. *Clinics in geriatric medicine*, *27*(1), 1-15.

Zhang, M. (2017). A Geographical Analysis of Food Access in the Greater Hartford Area of Connecticut. (Doctoral dissertation). University of Connecticut Graduate School.

Chapter 2 : Socio-demographic, socio-economic and health need differences between types of care use in community-dwelling older adults

Abstract

This article aims to identify relations between socio-demographic/socio-economic characteristics and the use of informal and formal care. All analyses were performed on data from the Belgian Ageing Studies, a survey among community-dwelling older people (60+) in Belgium. Latent class analyses were used to identify types of care use and bivariate analyses were used to assess differences within these types. Eight different types were identified. Results demonstrate that the use of formal care increases with age and is not related to socio-economic status. The conclusion highlights how the complexity of different types of care use might be a challenge for our ageing society.

Keywords: informal care; formal care; older adults; socio-economic/socio-demographic characteristics

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2.1. Introduction

Worldwide, the population is ageing. In Belgium, for example, the percentage of people older than 65 years is predicted to grow from 18.3% in 2016 to 22.3% in 2030. The proportion of people aged 80 years and older is projected to increase from 5.5% to 6.5% in the same period (Federaal Planbureau, 2016). With increasing age, the possibility of becoming frail is growing, as is the accompanying need for care and support (Daniels et al., 2012; Regueras and Verniest, 2014). Responding to these developments, in many countries, there is increasing policy attention to 'ageing in place' and 'community-based care' (Sixsmith et al., 2008; Wiles et al., 2011). This attention responds to people indicating that they want to live independently in their own homes for as long as possible, with appropriate formal and informal assistance. It is part of a long-term care policy in which institutionalisation is only deployed when home care is no longer an option (Vermeulen and Declercq, 2011). These issues are increasingly recognised by policymakers. For example, in February 2016, the Belgian Federal Minister of Healthcare launched a project call for pilot projects developing strategies for chronic and integrated care for the ageing population (RIZIV, 2016). In recent years, preventive home-based support and health promotion for older people has gained more attention, with the aim of identifying older people who lack sufficient care (Stijnen et al., 2013). Accurate case-finding[2] for older people in need of care is extremely important in order to provide the appropriate care and support at the right time (Ross et al., 2011). Despite the evident need, 'preventive home visits' appear to have very limited results when studied. A possible explanation might be found in the fact that these interventions have been conducted in a general population of older people already benefiting from an elaborate level of assistance (Boumans et al., 2008). This emphasises the importance of accurate identification and case-finding for frail older adults who currently lack care (Sutorius et al., 2016). In order to maintain their independence and stay in their own home, older people are using a broad range of informal and formal assistance (Hoeck et al., 2011; Jacobs et al., 2016). Within older populations, access to informal and formal care services is extremely important for preventing illnesses, adapting therapies to changing needs, potentially reducing acute care costs and maintaining the health and well-being of the ageing population (Thorpe et al., 2011). Despite the fact that health needs and health services usage are higher among older groups, horizontal equity in care use remains relatively unexamined in the literature on older people (Allin et al., 2006; Artazcoz and Rueda, 2007). Access to care for older people continues to be a concern because as people grow older, they are more

[2] Case-finding is the application of a diagnostic test or clinical assessment in order to optimally identify those with the disorder with minimal false positives. Case-finding is often performed in a selected population at high risk of a condition (Mitchell et al., 2011).

vulnerable to physical and financial constraints that might impede the timely utilisation of the health-care services needed (Mobley et al., 2006). This is recognised by the European Commission, which stated in a recent report that health inequalities in European Union (EU) countries need to be reduced (OECD and EU, 2016). Most European countries have achieved universal (or near-universal) coverage of health-care costs for a core set of services, which usually includes consultations with doctors, tests and examinations, and hospital care. Nevertheless, large inequalities in health and life expectancy still exist between people with higher levels of education and income and the more disadvantaged (Draper and Fenton, 2014). This is largely due to the different exposure to health risks but also arises from disparities in access to high-quality care (Mackenbach et al., 2008; OECD and EU, 2016). Age seems to be a factor linked to unmet needs for medical care due to it being too expensive, there being too far to travel or it involving long waiting lists in most EU member states (Chaupain-Gauillot et al., 2015; Eurostat, 2016). Research shows that there are differences in the use of informal and formal care by older people according to their socio-demographic and socio-economic characteristics: people over 75 years, as well as those who are disabled, single or widowed, are more likely to receive informal help from outside the household (Broese van Groenou et al., 2006). Paraponaris et al. (2012) also found that socio-demographic and socio-economic characteristics were an important predictor for the use of informal and formal care by frail older people. They concluded that low socio-economic status increases difficulties in accessing formal care and that public policies should better support informal care. The results of research in the UK indicate that older individuals in receipt of a lower income are significantly less likely to visit a general practitioner, specialist or dentist, although they often express a greater need (Allin et al., 2006). Suanet et al. (2012) also discovered that societal determinants such as culture, welfare state context and demographic composition have a role in understanding care use. Other research indicates several health factors associated with access to and use of formal care, such as functional capacity and health status (Blomgren et al., 2008; Matthews, 2015). In most existing research about personal characteristics and formal/informal care use, either the receipt of formal care, informal care or a combination of both is investigated (Broese van Groenou et al., 2016; Carrière et al., 2006; Davey et al., 2005; Gannon and Davin, 2010). Several authors have already shown the existence of mixed care or support arrangements among home-care users (Hlebec, 2015; Hlebec and Flipovic Hrast, 2016; Pinquart and Sörensen, 2002). For example, Hlebec's (2015) case study in Slovenia investigated care arrangements among homecare users and gives information about how older adults combine informal care with formally provided care based on 22 activities of daily living (ADLs). Rodríguez (2013) also concluded that in Spain, 47.8% of community-dwelling older adults are receiving informal care, 4.9% formal care and 9.8% a combination of both. However, these studies did not investigate the different possible combinations of care providers within these arrangements. This is also stated by Carrière et al (2006), who indicated that although there are many studies on the use of

healthcare services among older adults, few have looked at the diverse combinations of formal and informal sources of assistance. While this research is without doubt very valuable, it focuses on a more restricted view of care combinations. In this article, more types and patterns of care use are investigated based on potential combinations of a broad range of care providers used by older adults in daily life. The perspective of this article is to go beyond the classical distinction between three patterns of care use (informal, formal and mixed care use). A good knowledge of the socio-demographic and socio-economic profiles of older people can give very useful information to provide the appropriate care and support at the right moment and can avoid people in need being left undetected (Broese van Groenou et al., 2006). In response to the aforementioned research gaps, the current article addresses the following research questions:

1. Which different patterns of formal and informal care use can be detected among Belgian community-dwelling older adults?
2. What is the relation between socio-demographic/socio-economic characteristics, health needs and these identified patterns of care use?

With the first research question, we aim to explore existing patterns of different informal, formal and mixed care usage among community-dwelling older adults, starting from their self-prescribed care usage. With the second research question, we investigate how socio-demographic/socio-economic characteristics and health needs relate within these patterns, with the aim of identifying groups that could benefit from using better preventive home-based support.

2.2. Methods

2.2.1. Data collection

The data used in this study is cross-sectional and originates from the Belgian Ageing Studies (BAS), a research project that explores the needs and aspects of quality of life among community-dwelling older adults (i.e. informal care, formal care, frailty, well-being, social participation, housing, etc.) by using a standardised survey (for a full description, see De Donder et al., 2014). The data for the current article were gathered between 2008 and 2014 from 38,066 community-dwelling older adults aged 60 years and over, living in 83 municipalities in the Dutch-speaking part of Belgium (Flanders) and in Brussels. The BAS project used a participatory peer-research method. It embraced older adults as essential partners in the project and as partners in the data collection. Older volunteers were recruited through local authorities and associations and trained in how to deliver and collect the questionnaires. The questionnaire was self-administered but, on request, the volunteers were allowed to clarify questions. If a respondent refused or had difficulty in filling in the questionnaire, the volunteer received a replacement address in the same quota category to obtain the intended sample size. The

respondent was free to participate, and anonymity was guaranteed. The respondent was assured of the right to refuse to answer, as well as of privacy. More information on the research methodology can be found in De Donder et al. (2014).

2.2.2. Sample

The municipalities involved decided voluntarily to participate in the research project. A representative sample was drawn in each participating municipality by randomly selecting community-dwelling older adults from relevant population registers, stratified by age (60–69, 70–79, 80+) and gender. The sampling fraction depended on the size of the municipality, varying between N = 109 and N = 984. This implies that the samples were representative for each municipality, not for the whole of Flanders. Only community-dwelling older people who received any type of care or assistance, plus older people who were shown to be in need of care and assistance but did not receive it, were included in the analysis in the current article (N = 12,481). The data consisted of 35.7% men and 64.3% women. In the sample, 26.9% of the older adults were aged between 60 and 69 years, 36.0% were aged between 70 and 79 years, and 37.1% were aged 80 years and over. Concerning their marital status, 56.4% of older adults were married, 33.5% widowed, 4.5% never married, 4.1% divorced and 1.6% cohabiting. In terms of education, 45.3% of older adults had completed only primary education (up to the age of 12 years) or had no qualification at all, while 11.7% had undertaken higher education. Finally, 21.0% of older adults had a monthly household income of under €1,000, 40.5% of €1,000–1,499, 18.8% of €1,500–1,999 and 19.7% of more than €1,999. According to the Comprehensive Frailty Assessment Instrument (CFAI) (De Witte et al., 2013), 23.5% of the sample appeared to be 'low' frail, 33.8% were 'moderate' frail and 42.7% were 'high' frail. The reference categories within the data of the BAS (representative of people aged 60 and over in the participating municipalities) were 45.6% low frail, 33.3% moderate frail and 21.1% high frail.

2.2.3. Measures

To measure informal and formal care use, respondents were asked if they received care from 15 different possible care providers (persons or organisations), both informal and formal. These different items were divided into seven categories of care use (0 = no, i.e. receiving no help from this category; 1 = yes, i.e. receiving help from this category). Four of the seven categories referred to informal care, that is, help and care from within: (1) the nuclear family (partner and/or children); (2) the extended family (grandchildren and/or other relatives); (3) friends and acquaintances; and (4) neighbours. The other three categories referred to formal care: (1) general practitioner; (2) home nursing; and (3) formal home assistance (home-care services, cleaning services, grocery services, chores services,

senior companion services, hot meals and/or day care/short-term care). In addition, an eighth category referred to a group of older people who indicated that they were in need of care and assistance but did not receive any such support. The following independent variables were measured:

- Socio-demographic characteristics: gender (male, female); age (60–69 years, 70–79 years, 80 years and over) and marital status (married, never married, divorced, cohabitating, widowed).
- Socio-economic characteristics: education (no education or primary education, lower-secondary education, higher-secondary education, higher education) and monthly household income (€500–999, €1,000–1,499, €1,500–1,999, more than €2,000).
- Health needs: being in need of help for three ADLs ('Do you need help with the following activities: personal care, household activities and personal mobility?' – yes/no).

Table 2. Classes of informal care and formal care use of community-dwelling older adults: results Latent Class Analysis (N = 12,235)

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

2.2.4. Statistical analyses

In a first step, latent class analysis (LCA) was performed to identify classes of informal care and formal care use among community-dwelling older adults. This technique is used to analyse relationships in categorical data and enables the characterisation of latent (unobserved) variables through analysing the structure of the relationships among several manifest (observed) variables. In this study, LCA categorised the groups of older people based on similarities in their informal and formal care use (McCutcheon, 1987). LEM software was used to conduct the LCA (Vermunt, 1997). To determine an optimal exploratory model, we started computing a latent class model with only one single latent class and increased the number of classes while checking for a model fit. The goodness of fit was assessed using the Akaike's Information Criterion (AIC) and Bayesian Information Criterion (BIC) of L-square. The lower the AIC and BIC, the better the model fit. To avoid creating too many classes of care use and to enhance manageability and interpretability, a model was accepted when both AIC and BIC showed negative values (Nylund et al., 2007). To detect boundary estimates, avoid local optima and ensure

that non-identified parameter estimates did not affect the values of the latent class probabilities, the chosen model was conducted 20 times using different starting values. We considered the best solution out of 20 as the global optimum (e.g. Van der Ark and Richards, 2006). In order to perform statistical analyses with classes derived from the LCA, we created a single latent variable with a set of underlying classes by modal class assignment (McCutcheon, 1987). The different classes were considered as a nominal variable in the final analytical model. In a second step, we analysed the data using the Statistical Package for the Social Sciences (SPSS), version 23, International Business Machines Corporation (IBM) using bivariate analyses. Chi-square analyses were performed to explore differences in socio-demographic/socio-economic characteristics and the health needs of older adults between the different classes of care use (developed by LCA in the first step). Additionally, we used standardised residuals to assess the strength of the difference between observed and expected counts and to investigate which cells were contributing the most to the chi-square value (Agresti, 2007). Standardised residuals greater than 2 are discussed.

Table 3. Overview of the nine different classes

Class	Receiving help or care from	Frequency (%)
Class 1	Nuclear family	2,486 (19.9%)
Class 2	Nuclear and extended family	2,346 (18.8%)
Class 3	All informal caregivers	765 (6.1%)
Class 4	All informal caregivers + general practitioner	1,018 (8.2%)
Class 5	All informal + formal care providers	847 (6.8%)
Class 6	Family (nuclear and extended) + all formal care providers	1,616 (12.9%)
Class 7	All formal care providers	558 (4.5%)
Class 8	Formal home assistance	2,368 (19.0%)
Class 9	Nobody	477 (3.8%)

2.3. Results

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

Table 2 reports the results of the LCA. When both the AIC and BIC showed negative values, LCA reported eight different classes of care use among community-dwelling older adults (AIC = –2,8781, BIC = –477.2497). The first three classes of care use were characterised by older adults who were more likely to receive care that was dominated by informal caregivers. Class 1 represented 19.9% of the sample and consisted of older care recipients who were more likely to receive care only from nuclear family caregivers, that is, care from their spouse and/or children. Class 2 (18.8% of the sample) identified care recipients who were more likely to receive care from both nuclear and extended family caregivers, that is, care from their spouse, children, grandchildren and/or other relatives. Class 3 (6.1%

of the sample) comprised older people who were more likely to receive care from all different types of informal caregivers, that is, nuclear and extended family caregivers, friends and acquaintances, and neighbours. Second, there were three classes of care use characterised by older adults who were more likely to receive care from both informal caregivers and formal care providers. Class 4 (8.2% of the sample) identified older adults who were more likely to receive care from all informal caregivers in combination with care from their general practitioner. Older care recipients in class 5 (6.8% of the sample) were more likely to receive care from all informal caregivers in combination with care from all formal care providers, that is, care from their general practitioner, home nursing and formal home assistance. Class 6 represented 12.9% of the sample and consisted of older people who were more likely to combine informal care from their family (both nuclear and extended) with formal care from all formal care providers. Finally, two classes of care use consisted of older adults who were more likely to receive care dominated by formal caregivers. Class 7 (4.5% of the sample) comprised older care recipients who were more likely to receive care from all formal caregivers. Class 8 represented 19.0% of the sample and consisted of older people who were more likely to receive formal home assistance. Furthermore, 477 (3.8%) older adults reported to be in need of care but did not receive it (class 9). They were added as an additional class. An overview of the nine classes can be found in table 3.

2.3.2. Differences in informal and formal care use

By means of Chi-square analyses, we compared these nine different classes according to their socio-demographic/socio-economic characteristics and health needs (see table 4). We found several significant relationships between the socio-demographic/socio-economic characteristics, health needs and different classes. The standardised residuals allowed us to investigate which classes were contributing the most to the Chi-square value. These results are described in the following.

Gender

Compared to the other classes, older people who received care from all informal caregivers in combination with their general practitioner were more likely to be male (class 4, 43%). Likewise, people who reported that they were in need of care and support but were not receiving it from anyone were more likely to be male (class 9, 43.2%).

Age

Older adults who were receiving care from their nuclear family caregivers (class 1, 39.1%), from different kinds of informal caregivers (both nuclear and extended family, friends, and neighbours) (class 3, 32.8%) and from all informal caregivers in combination with their general practitioner (class 4, 35.7%) were more likely to be younger (60–69 years). Also, the group of people who reported that they were in need of help but were not receiving it from anyone tended to be younger (60–69 years) (class 9, 43.2%). People who were receiving care and support from both their nuclear and extended family (class 2, 39.9%) and also from all informal and formal care providers (class 5, 50.5%), from family caregivers (both nuclear and extended) in combination with formal caregivers (class 6, 56.7%), and from all formal caregivers (class 7, 46.2%) were more likely to be aged 80+.

Marital status

Older adults who were receiving help and support from their nuclear family (class 1, 67.1%), from family caregivers (both nuclear and extended) (class 2, 61.5%) and from all informal caregivers combined with their general practitioner (class 4, 66.8%) were more likely to be married. Older adults who were receiving help from all informal caregivers (class 3, 9.7%), from all informal and formal caregivers (class 5, 6.7%), from all formal caregivers (class 7, 19.7%), and formal home assistance (class 8, 5.8%) were more likely never to have been married. Older adults who were receiving help from all formal caregivers (class 7, 7.1%) and formal home assistance (class 8, 5.0%) were more often divorced, while older adults who received support from all informal caregivers (class 3, 38.2%), from all informal and formal caregivers (class 5, 43.0%), from a combination of family caregivers (nuclear and extended) and formal caregivers (class 6, 45.4%), from all formal caregivers (class 7, 44.3%), and formal home assistance (class 8, 36.4%) were more likely to be widowed. Older people indicating that they were in need of care and support but who were not receiving it from anyone were more often married (class 9, 65%) or divorced (class 9, 7.1%).

Education

Older adults receiving help from family caregivers (both nuclear and extended) (class 2, 49.1%) and from family caregivers (both nuclear and extended) in combination with all formal caregivers (class 6, 55.6%) more often tended to have no education, or only primary education. Older adults who were receiving help from all informal caregivers (class 3, 17.2%) and formal home assistance (class 8, 14.8%) were more likely to have undertaken higher education. Also, older people indicating that they were in need of care and support but were not receiving it from anyone were more often highly educated (class 9, 24.2% higher-secondary education and 18.5% higher education).

Income

Older adults who received care from family caregivers (nuclear and extended) in combination with formal caregivers (class 6, 25.5%), from only formal caregivers (class 7, 23.1%) and formal home assistance (class 8, 23.1%) were more likely to have a lower household income (€500–999). Older people who received help from all informal and formal caregivers (class 5, 45.3%) and from family caregivers (nuclear and extended) in combination with formal caregivers (class 6, 46.9%) more often had an income of €1,000–1,499. Older people who were more likely to receive care from the nuclear family (class 1, 21.2% and 25.3%) and from all informal caregivers in combination with their general practitioner (class 4, 21.9% and 23.4%) often had the highest incomes (€1,500–1,999 and €2,000+). Older adults who indicated they were in need of care and support but did not receive it from anyone also tended to have a high income (≥€2,000+) (class 9, 31.2%).

Health needs

Older adults who received care from all informal and formal caregivers (class 5, 35.0%), from family caregivers (nuclear and extended) and formal caregivers (class 6, 60.6%), and from all formal caregivers (class 7, 30.6%) reported more often that they were in need of help with ADLs (personal care, household activities and personal mobility).

Table 4. Socio-demographic and socio-economic characteristics of older people according to their class of care use

Socio-demographic, socio-economic characteristics and health needs		Sample of care users	Classes of care use (%)									X^2
			Class 1	Class 2	Class 3	Class 4	Class 5	Class 6	Class 7	Class 8	Class 9	
Gender	Male	35.7%	36.3	34.2	37.9	43.0*	36.7	34.4	32.1	32.5	43.2*	54.695**
	Female	64.3%	63.7	65.8	62.1	57.0	63.3	65.6	67.9	67.5	56.8	
Age	60-69	26.9%	39.1*	23.0	32.8*	35.7*	15.4	14.2	19.6	23.1	44.9*	874.035**
	70-79	36.0%	37.4	37.1	34.6	38.6	34.1	29.2	34.2	38.6*	36.3	
	80+	37.1%	23.5	39.9*	32.5	25.7	50.5*	56.7*	46.2*	38.3	18.9	
Marital status	Married	56.4%	67.1*	61.5*	44.9	66.8*	45.3	50.6	28.7	51.4	65.0*	1030.139**
	Never married	4.5%	4.7	0.8	9.7*	0.6	6.7*	1.1	19.7*	5.8*	5.8	
	Divorced	4.1%	4.3	2.6	5.6	4.2	4.0	2.2	7.1*	5.0*	7.1*	
	Cohabitating	1.6%	1.9	2.0	1.6	2.0	1.1	0.7	0.2	1.5	2.6	
	Widowed	33.5%	22.0	33.1	38.2*	26.4	43.0*	45.4*	44.3*	36.4*	19.5	
Education	No ed. - prim. ed	45.3%	41.7	49.1*	37.3	45.0	49.6	55.6*	47.2	41.4	33.0	256.776**
	Lower sec. ed.	26.0%	27.0	26.3	26.0	24.6	25.9	26.4	26.4	25.2	24.2	
	Higher sec. ed.	17.0%	18.5	14.8	19.6	19.2	15.1	12.4	14.6	18.6	24.2*	
	Higher ed.	11.7%	12.7	9.8	17.2*	11.3	9.4	5.7	11.8	14.8*	18.5*	
Income	500€-999€	21.0%	17.2	21.4	18.4	14.9	22.5	25.5*	31.1*	23.1*	15.7	281.471**
	1000€-1499€	40.5%	36.3	40.3	38.8	39.8	45.3*	46.9*	42.2	40.7	33.9	
	1500€-1999€	18.8%	21.2*	19.3	21.6	21.9*	16.4	16.2	17.0	16.5	19.2	
	More than 2000€	19.7%	25.3*	19.0	21.2	23.4*	15.8	11.4	9.7	19.7	31.2*	
Need of help for 3 activities	Pers. care, household act., pers. mobility	23.1%	13.3	17.1	9.2	13.2	35.0*	60.6*	30.6*	17.9	8.5	2604.492**

Note. * = standardised residuals greater than |2|; ** = p ≤ 0.001

2.4. Discussion

In this article, we have investigated different types of care use and how socioeconomic/socio-demographic characteristics and the care needs of older adults relate to their care utilisation. By using data from the BAS (De Donder et al., 2014) and by performing LCA, we created classes of informal and formal care use. We furthermore compared the nine different classes according to their socio-demographic/socioeconomic characteristics and their health needs. The first research question concerned the identification of patterns of care use by community-dwelling older adults. Classically, research about patterns of formal and informal care describes a care mix consisting of three types of care use among older adults: the use of formal care; the use of informal care; and/or a combination of formal and informal care use (Broese van Groenou et al., 2016; Gannon and Davin, 2010). However, this study identified eight different classes of care use among community-dwelling older adults and showed a more diversified and detailed pattern of care combinations. They are delivered by different combinations of a broad range of informal and formal care providers: the nuclear family (partner and/ or children) (class 1); the nuclear and extended family (grandchildren and/or other relatives) (class 2); all informal caregivers (class 3); all informal caregivers and the general practitioner (class 4); all informal and formal care providers (class 5); the nuclear and extended family in combination with all formal care providers (class 6); all formal care providers (class 7); and formal home assistance (home-care services, cleaning services, grocery services, chores services, senior companion services, hot meals and/or day care/short-term care) (class 8). This is in accordance with recent research indicating the existence of mixed care networks for community-dwelling older adults (Broese van Groenou et al., 2016; Hlebec, 2015; Hlebec and Flipovic Hrast, 2016). Nevertheless, there are some national particularities: Haberkern and Szydlik (2010) discovered that older adults use formal care services more frequently in Northern European countries because intergenerational care is less prevalent than in Southern and Central European countries. There are also other societal conditions that determine older adults' care use: older adults are more likely to receive only formal home care or a combination of formal and informal care in countries with more extensive welfare state arrangements (national health insurance, higher pensions, etc.) (Suanet et al., 2012). Looking at the Belgian welfare system in particular, on the one hand, nursing and personal care, both in residential care facilities and at home, are largely part of the public health-care system, which combines universal coverage with relatively low rates of out-of-pocket payment. On the other hand, the availability of home help, which is organised and subsidised by regional authorities, is limited through yearly quotas (Geerts and Van den Bosch, 2012). Although the contribution made by informal caregivers has declined slightly over the last few decades, it is still, and by far, the biggest source of help for the elderly in Belgium (De Koker et al., 2007). Nevertheless, recent research about Belgium reports increasing transitions from informal care to formal care (Geerts and Van den Bosch, 2012). Based on our data, we found strong usage of both formal and informal care with a wide range of combinations in between. The second research question addressed the relation between socio-demographic/socio-

economic characteristics and care needs, on the one hand, and types of care use, on the other, in order to have a better scope for preventive health initiatives among community-dwelling older adults. This study shows that older people who were receiving help from their nuclear family (class 1) or extended family (class 2) were more often married; older people who were receiving only formal care (classes 7 and 8) more often had no partner (i.e. never married, widowed or divorced). Broese van Groenou et al. (2006) clearly report that marital status influences the use and availability of informal help. On the other hand, we noticed that when people used a combination of informal and formal care (classes 5 and 6) or intensive formal care (class 7), they were more often older (80+) and in need of help with personal care, household activities and personal mobility. This is in line with research indicating that the amount and frequency of care use increases with age (Byrne et al., 2009; Regueras and Verniest, 2014). Older adults who received informal care from their nuclear family or a combination of informal care and their general practitioner more often had higher household income. Older adults who received different forms of formal care and less informal care more often had the lowest incomes (€500–999). Older adults within the class of people receiving care from family caregivers (both nuclear and extended) (class 2) or in the class that combines care from family (both nuclear and extended) with care from all formal care providers (class 6) were more often uneducated or had only primary education. This contradicts existing research from Broese van Groenou et al. (2006), which found that low socio-economic status impedes the access and use of formal care. A possible explanation can be found in the very accessible and widespread Belgian system of health care and social security, with low income-related patient contributions (RIZIV, 2016). The group of older adults that indicated they were in need of care or support but were not receiving it from anyone (class 9) were more often married people aged 60–69 years old, who had a high education and a high monthly household income (€2,000+).

2.4.1. Limitations and future research

This analysis in this article has some limitations. Although this research indicates that older care recipients can receive care and support from a broad range of both formal and informal care providers, it is not clear which caregiver or intervention contributes the most to their ability of self-manage or delays the institutionalisation of community-dwelling older people. Recently, research has been conducted examining the effectiveness of home-care interventions for frail older people (De Almeida Mello et al., 2016; Van Durme et al., 2015). Further research could explore the effectiveness of informal and formal care interventions within the different classes of care use. A second limitation can be found in the origin of the data sample. While all included individuals were older people who received some form of help or assistance or who indicated that they were in need of care and assistance but did not receive it, there was no comparison made with their level of frailty. Research indicates that some socio-economic or socio-demographic characteristics are risk characteristics for frailty (e.g. increased age, having no partner, lower educational level, lower income) (Dury et al., 2016). It would be interesting to identify highly frail people

within the different classes in order to customise care and support at the right time and tackle unmet needs. Third, due to the cross-sectional nature of the data, it is not possible to make causal statements about the relationship (Field, 2009). For that reason, we cannot determine whether some socio-economic and socio-demographic characteristics influence the care use classes or vice versa (despite gender and age). Future research could provide evidence related to the temporality of these relationships. Finally, a more qualitative approach could be useful to enhance understanding of the mechanisms and reasons behind the care use of older adults. This will form the topic of a subsequent article.

2.5. Conclusion and policy implications

Several types of formal and informal care use can be identified within our data, with a broad range of formal and informal care providers involved. This study gives insight into the complexity of the care mix among community-dwelling older adults. This study also indicates that there were still a certain number of older people who indicated that they were in need of care and support but did not receive it from anyone. A remarkable feature is that this group of people do not seem to have a low socio-economic status. People who used formal care or all possible caregivers were more often older, while people who were using informal caregivers were more likely to be younger. Older people who benefited from informal care were more often higher educated and had a higher monthly household income, while older adults who only received different forms of formal care more often had the lowest incomes. It seems that social capital goes with economic capital among older people. There is some evidence that a good education leads to better-paid occupations and thus to more wealth and better pensions in later life (Bosma et al., 1999; Grundy and Slogett, 2003). Research by Chapell and Blandford (1991) has already stated that, in the first instance, older people use their informal network to deal with their care needs and then progressively use formal care as they become older, face higher needs or when an informal network is lacking. Habib et al. (1993) also came to the conclusion that when older people live alone, the formal system replaces the family. Socio-economic characteristics (level of education and income) have no significant relation with the access and use of formal care. This emphasises the fact that Belgium has a high-performing and accessible health-care system. Although people with lower monthly household incomes do not experience barriers in accessing formal care, they seem to lack informal care and support. This emphasises that case-finding is extremely important to ensure that interventions target older people with defined care needs and to identify those people lacking care and support. Community-centered care, recognising different access to formal and informal resources, might provide an answer to that.

References

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

Allin, S., Masseria, C. and Mossialos, E. (2006). Inequality in health care use among older people in the United Kingdom: an analysis of panel data. *LSE Health*, *1*(1), 1–18.

Artazcoz, L. and Rueda, S. (2007). Social inequalities in health among the elderly: a challenge for public health research. *Journal of Epidemiology and Community Health*, *61*(6), 466–7.

Blomgren, J., Martikainen, P., Martelin, T. and Koskinen, S. (2008). Determinants of home-based formal help in community-dwelling older people in Finland. *European Journal of Ageing,5*, 335–47.

Bosma, H., Schrijvers, C. and Mackenbach, J.P. (1999). Socioeconomic inequalities in mortality and importance of perceived control: cohort study. *BMJ*, *319*(7223), 1469–70.

Boumans, A., Van Rossum, E., Nelemans, P., Kempen, G.I.J.M. and Knipschild, P. (2008). Effects of intensive home visiting programs for older people with poor health status: a systematic review. *BMC Health Services Research, 8*(1), 74.

Broese van Groenou, M., Glaser, K., Tomassini, C. and Jacobs, T. (2006). Socioeconomic status differences in older people's use of informal and formal help: a comparison of four European countries. *Ageing & Society, 26*(5), 745–66.

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

Byrne, D., Goeree, M.S., Hiedemann, B. and Stern, S. (2009). Home health care, informal care and family decision making. *International Economic Review, 50*(4), 1205–42.

Carrière, Y., Martel, L., Légaré, J. and Morin, L. (2006). Socio-demographic factors associated with the use of formal and informal support networks among elderly Canadians, in Z. Yi, E.M. Crimmins, Y. Carrière and J.M. Robine (eds) *Longer life and healthy aging*, Netherlands: Springer, pp 287–304.

Chappell, N. and Blandford, A. (1991). Informal and formal care: exploring the complementarity. *Ageing and Society, 11*(3), 299–317.

Chaupain-Guillot, S. and Guillot, O. (2015). Health system characteristics and unmet care needs in Europe: an analysis based on EU-SILC data. *The European Journal of Health Economics, 16*(7), 781–96.

Daniels, R., Van Rossum, E., Beurskens, A., Van den Heuvel, W. and De Witte, L. (2012). The predictive validity of three self-report screenings instruments for identifying frail older people in the community. *BMC Public Health, 12*, 69.

Davey, A., Femia, E.E., Zarit, S.H., Shea, D.G., Sundtström, G., Berg, S., Smyer, M.A. and Savla, J. (2005). Life on the edge: patterns of formal and informal help to older adults in the United States and Sweden. *The Journal of Gerontology: Psychological Sciences and Social Sciences, 60(*5), 281–8.

De Almeida Mello, J., Declercq, A., Cès, S., Van Durme, T., Van Audenhove, C. and Macq, J. (2016). Exploring home care interventions for frail older people in Belgium: a comparative effectiveness study. *Journal of the American Geriatrics Society, 64(*11), 2251–6.

De Donder, L., De Witte, N., Verté, D., Dury, S., Buffel, T., Smetcoren, A.S., Brosens, D. and Verté, E. (2014). Developing evidence-based age-friendly policies: a participatory research project, in *SAGE Research Methods Cases*, London: Sage Publications, pp 1–14.

De Koker, B., Jacobs, T., Lodewijckx, E. and Vanderleyden, L. (2007). Recente ontwikkelingen in gezinnen en families: implicaties voor de ouderenzorg, in B. Cantillon, K. Van den Bosch and S. Lefebure (eds) *Ouderen in Vlaanderen, 1975– 2005: een terugblik in de toekomst*, Leuven: Acco, pp 79–107.

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Schols, J. and Verté, D. (2013). The comprehensive frailty assessment instrument: development, validity and reliability. *Geriatric Nursing*, *34*, 274–81.

Draper, H. and Fenton, S.J. (2014). General patterns of health inequality are repeated in the older population, Birmingham: Birmingham Policy Commission, http://www.birmingham.ac.uk/Documents/research/policycommission/ healthy-ageing/3-General-patterns-of-health-inequality-are-repeated-in-theelderly-population-updated.pdf

Dury, S., De Roeck, E., Duppen, D., Fret, B., Hoeyberghs, L., Lambotte, D., Van der Elst, M., van der Vorst, A., Schols, J., Kempen, G., Zijlstra, G.A.R., De Lepeleire, J., Schoenmakers, B., Kardol, T., De Witte, N., Verté, D., De Donder, L., De Deyn, P.P., Engelborghs, S., Smetcoren, A. and Dierckx, E. (2016). Identifying frailty risk profiles of home-dwelling older peo.ple: focus on sociodemographic and socio-economic characteristics. *Aging & Mental Health, 7*, 1–9.

Eurostat (2016). Unmet health care needs statistics, http://ec.europa.eu/eurostat/ statistics-explained/index.php/Unmet_health_care_needs_statistics

Federaal Planbureau (2016). Bevolkingsvooruitzichten 2015–2060, Brussels, http:// www.plan.be/databases/data-35-nl-bevolkingsvooruitzichten+2015+2060

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

Gannon, B. and Davin, B. (2010). Use of formal and informal care services among older people in Ireland and France. *The European Journal of Health Economics, 11*(5), 499–511.

Geerts, J. and Van den Bosch, K. (2012). Transitions in formal and informal care utilisation amongst older Europeans: the impact of national contexts, *European Journal of Ageing, 9*(1), 27–37.

Grundy, E. and Sloggett, A. (2003). Health inequalities in the older population: the role of personal capital, social resources and socio-economic circumstances. *Social Science & Medicine, 56*(5), 935–47.

Haberkern, K. and Szydlik, M. (2010). State care provision, societal opinion and children's care of older parents in 11 European countries. *Ageing and Society, 30*(2), 299–323.

Habib, J., Sundstrom, G. and Windmiller, K. (1993). Understanding the pattern of support for the elderly: a comparison between Israel and Sweden. *Journal of Aging & Social Policy, 5*(1/2), 187–206.

Hlebec, V. (2015). Care arrangements among social home care users in Slovenia. *Studia Socjologiczne, 217*(2), 75–93.

Hlebec, V. and Flipovic Hrast, M. (2016). Influence of contextual and organisational factors on combining informal and formal care for older people. Slovenian case. *Research on Ageing and Social Policy, 4*(2), 30–54.

Hoeck, S., François, G., Geerts, J., Van der Heyden, J., Vandewoude, M. and Van Hal, G. (2011). Health-care and home care utilization among frail elderly persons in Belgium. *European Journal of Public Health, 22*(5), 671–6.

Jacobs, M., Van Tilburg, T., Groenewegen, P. and Broese van Groenou, M. (2016). Linkages between informal and formal care-givers in home-care networks of frail older adults. *Ageing and Society, 36*(8), 1604–24.

Mackenbach, J.P., Stirbu, I., Roskam, A.J.R., Schaap, M.M., Menvielle, G., Leinsalu, M. and Kunst, A.E. (2008). Socioeconomic inequalities in health in 22 European countries. *New England Journal of Medicine, 358*(23), 2468-481.

Matthews, D. (2015). Sociology in nursing 5: the effects of ageing on health inequalities. *Nursing Times, 111*(45), 18–21.

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

Mitchell, A.J., Hussain, N., Grainger, L. and Symonds, P. (2011). Identification of patient-reported distress by clinical nurse specialists in routine oncology practice: a multicentre UK study. *Psycho-Oncology, 20*(10), 1076–83.

Mobley, L.R., Root, E., Anselin, L., Lozano-Gracia, N. and Koschinsky, J. (2006). Spatial analysis of elderly access to primary care services. *International Journal of Health Geographics, 5*(19), 1-19.

Nylund, K.L., Asparouhov, T. and Muthèn, B.O. (2007). Deciding on the number of classes in latent class analysis and growth mixture modeling: a Monte Carlo simulation study. *Structural Equation Modeling, 14*(4), 535–69.

OECD (Organisation for Economic Co-operation and Development) and EU (European Union) (2016). *Health at a glance: Europe 2016 – State of health in the EU cycle*, Paris OECD: Publishing.

Paraponaris, A., Davin, B. and Verger, P. (2012). Formal and informal care for disabled elderly living in the community: an appraisal of French care composition and cost. *European Journal of Health Economics, 13*(3), 327–36.

Pinquart, M. and Sörensen, S. (2002). Older adults' preferences for informal, formal, and mixed support for future care needs: a comparison of Germany and the United States. *The International Journal of Aging and Human Development, 54*(4), 291–314.

Regueras, M. and Verniest, R. (2014). Vergrijzing en ouderenzorg in beeld – deel 1. *CM Informatie, 258*, 17–32.

RIZIV (Rijksinstituut voor ziekte- en invaliditeitsverzekering) (2016). Geïntegreerde zorg voor chronisch zieken, Brussels, http://www.inami.fgov.be/nl/professionals/ informatie-algemeen/Paginas/geintegreerde-zorg.aspx#.WD_zv_k19PY

Rodríguez, M. (2013). Use of informal and formal care among community dwelling dependent elderly in Spain. *European Journal of Public Health, 24*(4), 668–73.

Ross, S., Curry, N. and Goodwin, N. (2011). *Case management. What it is and how it can best be implemented*, London: The King's Fund.

Sixsmith, A. and Sixsmith, J. (2008). Ageing in place in the United Kingdom. *Ageing International, 32*(3), 219–35.

Stijnen, M.M.N., Jansen, M.W.J, Vrijhoef, H.J.M. and Duimel-Peeters, I.G.P. (2013). Development of a home visitation programme for the early detection of health problems in potentially frail community-dwelling older people by general practices. *European Journal of Ageing, 10*(1), 49–60.

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

Sutoris, F.L., Hoogendijk, E.O., Prins, B.A.H. and Van Hout, H.P.J. (2016). Comparison of 10 single and stepped methods to identify frail older persons in primary care: diagnostic and prognostic accuracy. *BMC Family Practice, 17*(1), 102.

Thorpe, J.M., Thorpe, C.T., Kennelty, K.A. and Pandhi, N. (2011). Patterns of perceived barriers to medical care in older adults: a latent class analysis. *BMC Health Services Research, 11*(1), 181.

Van Der Ark, L.A. and Richards, G. (2006). Attractiveness of cultural activities in European cities: a latent class approach. *Tourism Management, 27*(6), 1408–13.

Van Durme, T., Schmitz, O., Cès, S., Anthierens, S., Maggi, P., Delye, S., De Almeida Mello J., Declercq, A., Macq, J., Remmen, R. and Aujoulat, I. (2015). A comprehensive grid to evaluate case management's expected effectiveness for community-dwelling frail older people: results from a multiple, embedded case study. *BMC Geriatrics, 15*(1), 67.

Vermeulen, B. and Declercq, A. (2011). *Steunpunt WVG feiten & cijfers 15: Zorggebruik, -behoefte en -tevredenheid bij kwetsbare ouderen*, Leuven: LUCAS.

Vermunt, J.K. (1997). LEM: A general program for the analysis of categorical data, Tilburg: Tilburg University, http://www.camri.uqam.ca/camri/app/statistics/LCA/LEM/ manual.pdf

Wiles, J.L., Leibing, A., Guberman, N., Reeve, J. and Allen, R.E.S. (2012). The meaning of 'ageing in place' to people. *The Gerontologist, 52*(3), 357–66.

Appendix: questionnaire Belgian Ageing Studies

1. Zip code (please fill in): ……

2. Part of the municipality (please fill in): ……

3. How old are you (please fill in)?

…… years

4. Sex (please fill in):

1. Male	
2. Female	

5. Wich nationality do you have (please fill in)?

1. Belgian	
2. Other: ……..(please fill in)	

6. Which country were you born in (please fill in)?

1. Belgium	
2. Other: ……..(please fill in)	

7. What is your highest educational degree that you have obtained (please tick where applicable)?

1. No degree obtained		6. Higher vocational education	
2. Primary education		7. Higher technical education	
3. Lower secondary vocational education		8. Higher secondary education	
4. Lower secondary technical education		9. Higher non-university education	
5. Lower secondary education		10. University education	

8. Civil status: (please tick where applicable)

	YES	
1. Married		Since…
2. Never been married		
3. Divorced		Since…
4. Cohabitation		Since…
5. Widow(er)		Since…
6. Celibatarian		Since…

9. How many living children of your own/adopted do you have (please fill in)?

…… children

10. How many living grandchildren do you have (please fill in)?

…… grandchildren

11. Who else lives in your household besides you? (you may select more than one alternative)

	1. Yes	2. No
1. Partner		
2. Child(ren)		
3. Grandchild(ren)		
4. Parent(s)		
5. Other(s)		

12. What is or was your main occupation (please tick where applicable)?

1. Unskilled labourer		7. Farmer	
2. Skilled labourer		8. Professional	
3. Assistant of a self-employed person		9. Company manager	
4. Low-level office worker		10. Wholesaler	
5. High-level office worker		11. Other self- employed person	
6. Other type of employee		12. Housewife/-Husband	

13. How long have you been living in your municipality (please fill in)?

…… years

14. How old is your house (please fill in)?

…… years

15. Which statement regarding your house is applicable to you (please tick where applicable)?

1. I am the owner	
2. I am a tenant (private market)	
3. I am a tenant (council estate)	
4. None of the above	

16. What is your current housing situation (please tick where applicable)?

1. Living at home independently in a single-family house	
2. Living at home independently in an apartment	
3. Living at home independently in a studio apartment	
4. Living in with children	
5. Service flat	
6. Living together in group	
7. Kangaroo-living or intergenerational living	

17. Which statements are applicable to your house (please tick all appropriate items)?

1 = Not applicable at all
2 = Rather not applicable
3 = Neither applicable / nor inapplicable
4 = Rather applicable
5 = Completely applicable

	1	2	3	4	5
1. House is too big					
2. House is too small					
3. House is in a bad condition/poorly kept					
4. I have to walk up a flight of stairs to enter the house					
5. The thresholds are too high (inside or outside the house)					
6. There are stairs in the house					
7. I have to walk up the stairs to go to the toilet					
8. House is too expensive					
9. House runs the risk of being burglared					
10. House is not very comfortable					
11. House is too noisy (bad sound insulation)					
12. It is difficult to heat the house					
13. Insufficient comfort in the house					
14. I do not like the neighbourhood					
15. Distance to facilities is too big (e.g. shop, bank, etc.)					
16. Distance to children is too big					

18. Which of the following is available in your house (please tick 'yes' or 'no' where applicable)?

	1. Yes	2. No
1. Bath or shower		
2. Central heating		
3. Toilet inside the house		
4. Telephone		
5. Smoke detector		

19. What is your point of view regarding the following possibilities (please tick all appropriate items)?

1 = Extremely negative
2 = Rather negative
3 = Neither negative / nor positive
4 = Rather positive
5 = Extremely positive

	1	2	3	4	5
1. Leaving your house unchanged					
2. Adapting your house to your needs					
3. Moving to an adapted type of housing					
4. Moving to a retirement home / nursing home					
5. Moving in with your children					
6. Living together with a few older people, with separate living areas					
7. Moving to a service flat					

20. Have you moved in the previous 10 years (please tick where applicable)?

1. Yes	
2. No	

If 'yes', how many years ago? …… years

If 'yes' what was the zip code of your previous address? …… Zip code

If 'no', move on to question 22

21. Please indicate the most important motives/reasons to move (please tick yes or no):

	1. Yes	2. No
1. Loneliness		
2. Need for social contacts		
3. Not becoming independent of children		
4. Housing problems		
5. Health problems		
6. Financial situation		
7. Presence of several services in the local environment (bank, shop, etc.)		
8. Attractive environment		
9. Feelings of unsafety		

22. How often do you have contact with people living in your neighbourhood (please tick where applicable)?

1. Never	
2. Once a month or less	
3. Several times a month	
4. Once a week	
5. Various times a week or more	

23. How do you feel about this contact (please tick)?

1. Very negatively	
2. Rather negatively	
3. Neither negatively nor positively	
4. Rather positively	
5. Extremely positively	

24. How often do you leave your home in the evening? (please tick where applicable)?

1. Never	
2. Once a month or less	
3. Several times a month	
4. Once a week	
5. A couple of times a week or more	

25. How much do you enjoy living in your neighbourhood (please tick where applicable)?

1. Not at all	
2. Not really	
3. Neutral	
4. Much	
5. Very much	

26. To what extend do you feel connected with what is happening in your neighbourhood (please tick where applicable)?

1. Not connected at all	2. Not very connected	3. It's OK	4. Connected	5. Very connected

27. Which of the statements below are applicable to your neighbourhood (please tick 'yes' or 'no' for each case)?

	1. Yes	2. No
1. Not enough facilities		
2. Traffic is too heavy		
3. Few acquaintances/ friends/relatives living in this neighbourhood		
4. Unpleasant neighbourhood		
5. Only older people live in this neighbourhood		
6. Too many youngsters live in this neighbourhood		
7. Degeneration/ pollution		
8. Unsafety/ crime		
9. Bad mentality		
10. Obstacles in the living environment		
11. Too many foreigners in the neighbourhood		
12. Noise pollution		

28. Which of the facilities mentioned below are <u>insufficiently</u> present in your neighbourhood (please tick 'yes' or 'no' for each case)?

	1. Yes	2. No		1. Yes	2. No
1. Grocer's			13. Swimming pool		
2. Bank			14. Library		
3. Pharmacy			15. Community centre		
4. Family doctor (GP)			16. Lighting		
5. Butcher			17. Mobile shop		
6. Bakery			18. Cinema		
7. Benches			19. Theatre		
8. Public toilets			20. Post office		
9. Public transport			21. Pub		
10. Bus stop			22. Green area/ park		
11. Services centre			23. Pedestrian crossings		
12. Sports centre					

29. Do you think that in your neighbourhood sufficient events are being organised for the over-sixties (please tick when appropriate)?

1. Largely insufficient	2. Insufficient	3. So-so	4. Sufficient	5. More than sufficient

30. How do you get around (please tick all appropriate items)?

	1. Never	2. Less than 1x/ month	3. Monthly	4. 1 to 2 times/week	5. Almost daily
1. On foot					
2. Car					
3. Bicycle					
4. Bus/ tram / underground					
5. Train					
6. Taxi					
7. Ring and ride					
8. Transport organized by private/public services (ex. Mindermobielencentrale, transport with volunteers, …)					

31. To which extent do you agree with the following statements (please tick when appropriate)?

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

	1	2	3	4	5
1. These days, it is too dangerous to go out on the streets at night					
2. It is too dangerous to leave children alone on the street these days					
3. I seldom go out alone because I'm afraid of being assaulted and robbed					
4. One has to be extra careful on the streets at night					
5. Over the past 10 years the streets have become more dangerous					
6. I do not open the door when the bell rings in the evening and at night					
7. An alarm system is necessary these days					
8. When going on vacation I am afraid to leave my house unguarded					
9. I generally trust my neighbours to look out for my property					
10. People in my neighbourhood are very willing to help each other out					

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

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

	1	2	3	4	5
1. Last year, I have been assaulted or physically harmed by a person whom I knew					
2. Last year, I have been touched unwontedly or I was obliged to undress myself for a person whom I knew					
3. Last year, I have been forced by a person whom I knew, to sign papers or to give money or goods without my will					
4. Last year, I have felt anxious, ashamed or threatened by accusations of a person whom I knew					
5. Last year, I have experienced difficulties when I made an appeal on help from a person whom I knew (toilet, getting dressed, purchases, meals, household, taking medicines, receiving appropriate materials)					
6. Last year, a person who I knew, has hindered me to read my mail, to meet friends or acquaintances or to have leisure activities					

33. Considering the last few weeks, to which extent do you agree with the following statements (please tick all appropriate items)?

1 = Not at all
2 = Not more than usual
3 = More than usual
4 = Considerably more than usual

	1	2	3	4
1. I have trouble sleeping and often lay awake due to troubles				
2. I feel unhappy and depressed				
3. I feel like I'm losing my self-confidence				
4. I feel like I cannot cope with the problems				
5. I feel like I'm under constant pressure				
6. I feel like I'm not worth anything anymore				
7. I feel like my memory is letting me down				

34. 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

	1	2	3	4	5
1. I experience an emptiness					
2. There are enough people whom I can rely on when I'm in trouble					
3. I know many people whom I can rely on totally					
4. There are enough people with whom I feel a bond					
5. I miss having people around me					
6. I often feel like I've been left in the lurch					

35. Please choose the answer that most accurately describes the way you felt last week (please tick all appropriate items)?

	1. Yes	2. No
1. Are you generally satisfied with your life?		
2. Do you frequently feel bored?		
3. Do you often feel desperate?		
4. Would you rather stay at home than to go out and explore new activities?		
5. Do you feel useless at this moment?		

36. How often do you pay/receive a visit to/from or do you call over the telephone with (please tick all appropriate items):

	1. Never	2. Less than once per month	3. Monthly	4. 1 to 2 times/week	5. (Almost) daily	6. Not applicable
1. Children						
2. Son/Daughter-in-law						
3. Grandchildren						
4. Brothers/Sisters						
5. Parents						
6. Other relatives						
7. Friends/acquaintances						
8. Neighbours/People from the neighbourhood						

37. To which extent are you satisfied with your contacts with the following persons (please tick all appropriate items):

1 = Completely dissatisfied
2 = Rather dissatisfied
3 = Neither dissatisfied/nor satisfied
4 = Rather satisfied
5 = Very satisfied
6 = Not applicable

	1	2	3	4	5	6
1. Partner						
2. Children						
3. Son/Daughter-in-law						
4. Grandchildren						
5. Brothers/Sisters						
6. Parents						
7. Other relatives						
8. Friends/acquaintances						
9. Neighbours/people from the neighbourhood						

38. Have the following activities been hampered by your state of health, if so, for how long (please tick all appropriate items)?

	1. More than 3 months	2. 3 months or less	3. Not at all
1. Very demanding activities like lifting up heavy objects, etc.			
2. Less demanding activities (e.g. carrying shopping bags)			
3. Walking up a hill or some stairs			
4. Bending down, lifting up or bending over			
5. Going for a short walk			
6. Eating, dressing, taking a shower/bath or going to the toilet			
7. Household chores			
8. Social activities (e.g. visit family or friends)			

39. Did you start eating less in the last three months because of a lack of appetite, digestive disorders or problems with chewing and/or swallowing? (please tick)

1.	2.	3.
Yes, I have a very poor appetite	Yes, I have less appetite	No, my appetite hasn't changed

40. Did you lose weight in the past three months? (please tick)

1.	2.	3.
Yes, more than three kilo	Yes, between one and three kilo	No, I havent had any weight loss

41. How would you judge your nourishment situation? (please tick)

1.	2.	3.
Undernourished	Well nourished	I don't know

42. How would you describe your sense of hearing? (please tick)

1.	2.	3.
I hear well	I have poor hearing and I do not have a hearing aid	I have poor hearing but I have a hearing aid

43. How would you describe your visibility? (please tick)

1.	2.	3.
I have good eyesight	I have poor eyesight and I'm not wearing (good) glasses	I have poor eyesight but I'm wearing good glasses

44. Have you suffered a fall in the last 12 months? (please tick)

1. No		4. Yes, three times	
2. Yes, once		5. Yes, four times	
3. Yes, twice		6. Yes, more than four times	

45. Suppose you are unable to carry out the activities you usually do in the housekeeping for a certain while, whom would you be able to appeal to (please tick 'yes' or 'no' for each case)?

	1. Yes	2. No
1. Wife/husband		
2. Daughter		
3. Son		
4. Daughter-in-law		
5. Son-in-law		
6. Grandchild or great-grandchild		
7. Sister or brother (sister-in-law/brother-in-law)		
8. Other relatives		
9. Neighbour		
10. Friend/acquaintance		
11. Nobody		

46. Do you need assistance with (please tick 'yes' or 'no' for each case)?

	1.Yes	2. No
1. Your personal care		
2. Your housekeeping		
3. Personal mobility		

47. If you do get care, from which persons or organisations do you get assistance (please tick 'yes' or 'no' for each case)?

	1.Yes	2. No		1.Yes	2. No
1. Nobody			12. Home nursing		
2. Partner			13. Service for home care		
3. Children			14. Cleaning service		
4. Grandchildren			15. Grocery service		
5. Family/other relatives			16. Chores service		
6. Friends and acquaintances			17. Hot meals		
7. Neighbours			18. Social service centre		
8. Family doctor (GP)			19. Volunteers		
9. Organisation for the aged			20. Municipal authorities		
10. Home care			21. Less mobile service		
11. Service voucher			22. Day care/short-term care		

48. How many hours of assistance do you get every week (please fill in)?

…… hours/week

49. To which extent are you satisfied with the assistance offered by the following persons or organisations (please tick)?

1 = Not at all satisfied
2 = Rather dissatisfied
3 = Neither dissatisfied/nor satisfied
4 = Rather satisfied
5 = Very satisfied
6 = Not applicable

	1	2	3	4	5	6
1. Partner						
2. Children						
3. Grandchildren						
4. Family						
5. Friends and acquaintances						
6. Neighbours						
7. Family doctor (GP)						
8. Organisation for the aged						
9. Home care						
10. Dienstencheque						
11. Home nursing						
12. Service for home care						
13. Cleaning service						
14. Grocery service						
15. Chores service						
16. Hot meals						
17. Social service centre						
18. Volunteers						
19. Municipal authorities						
20. Less mobile service						
21. Day care/short-term care						

50. If this care is not good enough, why is that (please tick 'yes' or 'no' for each case)?

	1. Yes	2. No
1. Too little help		
2. Negative attitude of the care givers		
3. No or little help during the holiday periods		
4. No or little help during the weekend		
5. No or little help during the evening		
6. Help is not immediately available		
7. Too expensive		
8. Too much stress on the people around me		
9. Failing equipment		
10. Help at the wrong time of day		
11. Too many different care givers		

51. How often do you help ill, diseabled or elderly relatives, neighbours or friends? (please tick)

1= Never
2= Less than once per month
3= Monthly
4= Weekly
5= (Almost) daily
6= A few times a day

	1	2	3	4	5	6
1. Partner						
2. Children						
3. Son/daughter-in-law						
4. Grandchildren						
5. Brothers/sisters						
6. Parents						
7. Other relatives						
8. Friends/acquaintances						
9. Neighbours/people from the neighbourhood						

52. How often do you take care of your grandchildren? (please tick where applicable)

1. Never	2. Less than once per month	3. Monthly	4. Weekly	5. (Almost) daily	6. A few times a day

53. How often do you look after other little children from the neighbours, friends or other relatives? (please tick where applicable)

1. Never	2. Less than once per month	3. Monthly	4. Weekly	5. (Almost) daily	6. A few times a day

54. To which extent do you agree with the following statements (please tick where applicable)?

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

	1	2	3	4	5
1. When times get rough, elderly people usually suffer worst					
2. The elderly are a separate group in society with their own interests					
3. Society is especially focussed on youngsters, the interests of the elderly are not taken into account					
4. Some people act like I don't have anything left to contribute to society now that I'm older					
5. I have this feeling that the aged no longer count these days					
6. The elderly should have much more of a say in what is being organised for them					
7. Since I'm older, I have regularly noticed that people no longer take me seriously					

8.	Compared to other elderly people I'm very lucky					
9.	I have the feeling that the aged often are being considered less important or treated unfairly compared to other groups of people					
10.	I find it hard to be an elderly person					
11.	Today's elderly have more difficulties than in the past					

55. To which extents do you have/ have you had difficulties with the problems below (please tick all appropriate items)?

1 = Never
2 = Seldom
3 = Sometimes
4 = Often

		1	2	3	4
1.	Road unsafety				
2.	Lack of care				
3.	Insufficient possibilities to get together or relax in the neighbourhood				
4.	Insufficient possibilities for political participation				
5.	Lack of information and advice				
6.	Problems with filling in forms				
7.	Fear for robbery, theft or burglary in the house				
8.	Fear for being harassed on the street				

56. How often do you practise the following activities (please tick all appropriate items)?

1 = Never
2 = Seldom
3 = About monthly
4 = About weekly
5 = More than once a week

		1	2	3	4	5
1.	Going for a walk or cycling					
2.	Other sports					
3.	Playing cards or board games					
4.	Taking part in a play, folk dancing, choir					
5.	Doing odd jobs or handiwork					
6.	Going to bars or to restaurants (including brasserie and tea room)					
7.	Travelling and making excursions					
8.	Gardening					
9.	Reading books					
10.	Receiving training or taking a course					
11.	Reparations in the house					
12.	Shopping for pleasure					
13.	Going to a sports event					
14.	Going to the library					

57. To which extent are you a member of the following associations (please tick)?

1 = Never been a member 3 = Member
2 = Used to be a member 4 = Member of the board

	1	2	3	4
1. Environmental or anti-pollution organisation				
2. Fan club				
3. Organisation helping the disabled, the aged, people in need etc.				
4. Association for (amateur) artists (choir, theatre circles, literature, dance,...)				
5. Hobby club (cooking, sewing, collecting stamps, wine-tasting etc.)				
6. Women's association (KAV, SVV, etc.)				
7. Socio-cultural association (KWB, Davidsfonds, Vermeylenfonds, etc.)				
8. Sports association or club (including walking, playing chess, etc.)				
9. A political association or party				
10. A religious or ecclesiastical association (parochial work, etc.)				
11. Neighbourhood or residents' association (carnival- and/or festive associations, etc)				
12. Association devoting itself to international peace and to the development of Third World countries				
13. Trade union, organisation for small businesses, professional organisation or organisation for employers and self-employed people				
14. Municipal advisory body/ advisory committee on education				
15. Family associations (Gezinsbond etc.)				
16. Associations linked to a local bar (darts, slate club, pigeon fanciers' association, …)				
17. Red cross, Flemish Cross, volunteer firemen, etc.				
18. Association for the elderly				
19. Self-help group				
20. Youth movement or youth association				

58. How important were following reasons for becoming a member of an association (please tick all items)?

1 = Very unimportant 4 = Rather important
2 = Rather unimportant 5 = Very important
3 = Nor unimportant/nor important

	1	2	3	4	5
1. Because of the cosiness					
2. Because you get to see people					
3. To meet new people					
4. To support the idea/goals of the association					
5. I am asked to become a member					
6. To help and support the association					
7. Because of my partner					
8. Because it's important to contribute to society					
9. To learn new things					
10. To spend my time productively					
11. To feel myself needed					
12. Because it is in my neighbourhood					

59. Please indicate how important following reasons were to not visit activities/meetings of the association more often (please tick all appropriate items)?

1 = Very unimportant
2 = Rather unimportant
3 = Nor unimportant/nor important
4 = Rather important
5 = Very important

	1	2	3	4	5
1. Health problems					
2. Transportation problems					
3. No time					
4. Taking care for someone					
5. The activities do not appeal to me					
6. The atmosphere does not appeal to me/Not cosy					
7. I do not have anyone to go with					
8. I did not now it existed					
9. Not interested					
10. Too expensive					
11. Activities are often in the evening					
12. Fear of coming out on the streets					
13. I have never done it before					
14. Conflicts within the organisation					

60. Which of the following activities organised by associations would be of interest to you (please tick 'yes' or 'no' for each item)?

	1. Yes	2. No
1. Members' meetings		
2. Position on the board/board meetings		
3. Celebrations, get-togethers, recreation with animation		
4. Afternoons for debating (discussions, lectures)		
5. Afternoons for reflection/religious celebrations		
6. Practical courses (e.g. secretarial work, computer, etc.)		
7. Series of lessons		
8. Voluntary activities (e.g. visiting patients, retirement home activities, etc.)		
9. Social actions (e.g. Levenslijn)		
10. Guided visits (museums, companies, etc.)		
11. Attending performances at the theatre, films, concerts		
12. Sports activities		
13. Hobby workshops		
14. Theatre and singing activities		
15. Harmony/brass band		
16. Day or half-day excursions		
17. Joint activities with other associations for the elderly		
18. Pilgrimages		
19. Holidays in Belgium		
20. Holidays abroad		
21. Members' magazine/board magazine		

61. Do you know of the existence of associations for the elderly in your municipality? (please tick where applicable)

1. Yes	
2. No	

62. Are you a member of an association for the elderly? (please tick where applicable)

1. Yes	
2. No	

63. Do you expect to become a member of an association for the elderly in the years to come? (please tick where applicable)

1. No	2. I don't think so	3. Yes, maybe	4. Yes

64. In following table different types of voluntary work are grouped. Which type of volunteering do you perform (please tick 'yes' or 'no' for each item)?

	1.Yes	2. No
1. Recreational: e.g. organising or accompanying trips/vacations		
2. Handicraft: e.g. organising hand work/ tinkering		
3. Company: e.g. house visits/ sick visits/ volunteer in a nursing home		
4. Household: e.g. offering kitchen aid/ meal aid/ refurnishing/ aid in gardening		
5. Courses: e.g. organising/supporting scientific work, education, trainings, workshops, study counselling, reading books, etc.		
6. Care: e.g. organising/ supporting (baby)sitters, nursing, baby care, assisted living		
7. Socio-cultural: e.g. organising/supporting of theatre and music-events		
8. Administrative: function in board of association, supporting in accounting, administration, redaction, etc.		
9. Societal: e.g. supporting actions for charity		
10. Governmental: e.g. representation in senior advisory board in the municipality		

65. How often do you perform voluntary work? (please tick where applicable)

1. Never	2. Less than once per month	3. Monthly	4. Weekly	5. (Almost) daily

If you don't do volunteer work, do you expect to do so in the years to come? (please tick where applicable)

1. No	2. I don't think so	3. Yes, maybe	4. Yes

66. How important were following reasons to perform voluntary work (please tick all appropriate items)?

1 = Very unimportant
2 = Rather unimportant
3 = Nor unimportant/nor important
4 = Rather important
5 = Very important

	1	2	3	4	5
1. Because of the cosiness					
2. Because you get to see people					
3. To meet new people					
4. To support the idea/goals of the association					
5. I am asked to become a member					
6. To help and support the association					
7. Because of my partner					
8. Because it's important to contribute to society					
9. To learn new things					
10. To spend my time productively					
11. To feel myself needed					
12. Because it is in my neighbourhood					

67. Please indicate how important following reasons are that stop you from doing more voluntary work (please tick)?

1 = Very unimportant
2 = Rather unimportant
3 = Nor unimportant/nor important
4 = Rather important
5 = Very important

	1	2	3	4	5
1. Health problems					
2. Transportation problems					
3. No time					
4. Taking care for someone (e.g. older family members, children, …)					
5. The activities do not appeal to me					
6. The atmosphere does not appeal to me/not cosy					
7. I do not have anyone to go with					
8. I did not know it existed					
9. Not interested					
10. Reimbursement doesn't cover all expenses					
11. Activities are often in the evening					
12. Fear of coming out on the streets					
13. I have never done it before					
14. Conflicts within the organisation					

68. Some people follow everything what is happening in politics, while others are not interested at all. How do you feel about politics? Are you … (please tick one box)

1. Not interested at all	
2. Rather not interest	
3. Neither not interested/nor interested	
4. Rather interested	
5. Very interested	

69. Could you indicate with a number from 1 until 5 how good you think the influence of older people is on … (please tick all items)

1 = Very poorly
2 = Rather poorly
3 = Neither poorly/nor good
4 = Rather good
5 = Very good

	1	2	3	4	5
1. The policy of social housing companies					
2. Local policy					
3. Local advisory boards					
4. Policy of health care organisations and institutions					
5. Policy of home care institutions					
6. Policy of associations that organise activities for older people					
7. The design of the neighbourhood (e.g. liveability of the neighbourhood)					
8. Social policy (OCMW)					

70. On average, how many hours of television do you watch daily (please fill in)?

…… hours a day

71. How often do you read the newspaper (please tick where applicable)?

1. Never	
2. Less than once a week	
3. Weekly	
4. Daily	

72. Do you often consult the municipal information leaflet (please tick where applicable)?

1. Yes	2. No	3. I don't know it

73. How often do you use the internet (please tick where applicable)?

1. Never	
2. Less than once a week	
3. Weekly	
4. Daily	
5. Several times a day	

74. Why do you use the internet? (please tick 'yes' or 'no' for each item)

	1. Yes	2. No
1. To browse and search for information		
2. E-mail		
3. Communication with the government		
4. Communication with children and grandchildren		
5. Social media (facebook, twitter, …)		
6. Skype		
7. Online shopping		

75. To which extent are you satisfied with the following services (please tick)?

1 = Not satisfied
2 = Satisfied
3 = No appeal made to

	1	2	3
1. Opening hours of the municipal services			
2. Accessibility of the municipal services			
3. Services offered by the municipal services			
4. The attitude of the municipality's officials			
5. Opening hours of the OCMW services			
6. Accessibility of the OCMW services			
7. Services offered by the OCMW services			
8. Attitude of the OCMW services officials			
9. Services at the police station			
10. Visibility of policemen on the street			
11. Services provided by the social service centre			
12. Cultural policy of the municipality			
13. Accessibility of the library			
14. The offer of books in the library			
15. The services offered by the library			
16. The greens present in the municipality			
17. Condition of the pavements			
18. Road safety policy in the municipality			
19. Offer of public transport in the municipality			
20. Sports and recreational possibilities for the elderly people			
21. Waste collection			
22. Frequency of garbage collection			
23. Quality of the dustbin bags			
24. Opening hours of the selective waste collection site (container park)			
25. Selective waste collection site (container park) accessibility			
26. Service at the selective waste collection site (container park)			
27. Rooms available for rent from the municipality			
28. Price of the rooms made available by the community			
29. Grants/subsidy/support for housing adaptations			
30. Warm meals			
31. Cleaning services			
32. Chores services			

33. Grocery service			
34. Day care			
35. Short-term care			
36. Home care			
37. Social housing			
38. Home nursing			
39. Sociaal huis			

76. When you want information about services/financial incentives, who would you contact (please tick 'yes' or 'no' for each item)?

	1. Yes	2. No
1. Child(ren)		
2. Grandchild(ren)		
3. Neighbours		
4. Family		
5. Local authorities		
6. Social services		
7. Sickness insurance		
8. Family doctor (GP)		
9. Sociaal huis		
10. Others		

77. How often do you attend the cultural events listed below (please tick all appropriate items)?

		1. Never	2. Once a year	3. Several times a year	4. Once a month	5. Several times a month
Theatre	1.Classical theatre					
	2.Contemporary theatre					
	3.Comedy					
	4.Cabaret					
Dance	5.Classical ballet					
	6. Contemporary dance					
	7. Performances					
Music	8.Classical music					
	9.Folk/ world music					
	10. Cabaret					
	11. Flemish music					
	12. Jazz					
	13. Rock/pop/ hip-hop					
	14. Opera					

	15. Light opera					
Film	16. Commercial film					
	17. Non-commercial film (Arthouse film)					
Art	18. Arts with an educational function					
	19. Classical arts (fine arts)					
	20. Contemporary art					
Popular culture	21. Fun fair, carnival, jumble/rummage sale, circus, …					

78. Which aspects keep you from attending cultural events more often (please tick 'yes' or 'no' for each item)?

	1.Yes	2.No
1. No interest		
2. Lack of time		
3. Timing of the performance (at night)		
4. Distance		
5. Lack of own transportation		
6. Lack of public transport		
7. Reservation		
8. Too expensive financially		

79. In which category would you classify your net monthly household income at this moment (sum of your pension and all other revenues, including from real estate), (please tick)?
Living together with your partner: also add the revenues of your partner
Single: personal monthly income available

1. Between 500 and 999 euros (20,000 and 39,999 BEF)	
2. Between 1,000 and 1,499 euros (40,000 and 59,999 BEF)	
3. Between 1,500 and 1,999 euros (60,000 and 79,999 BEF)	
4. Between 2,000 and 2,499 euros (80,000 and 99,999 BEF)	
5. Between 2,500 and 3,999 euros (100,000 and 159,999 BEF)	
6. Between 4,000 and 4,999 euros (160,000 and 199,999 BEF)	
7. More than 5,000 euros (200,000 BEF)	

80. How does your household get by with the total household income (please tick where appropriate)?

1. Very poorly		4. Rather easily	
2. Poorly		5. Easily	
3. Rather poorly		6. Very easily	

81. At what age did you stop working? ((early) retirement) (please fill in)

…….years

82. Please indicate how important following reasons were in your decision to go into retirement? (please tick all appropriate items)

1 = Very unimportant
2 = Rather unimportant
3 = Nor unimportant/ nor important
4 = Rather important
5 = Very important

	1	2	3	4	5
1. It was an obligation (shut-down, reorganisation, …)					
2. To make room for the younger generation					
3. I had sufficient/enough financial means to go into retirement					
4. The financial difference between working and retirement was very little/negligible					
5. Due to health reasons (physical and/or psychological)					
6. Dissatisfaction with jobcontent (little promotion prospects, little variation,…)					
7. Dissatisfaction with working circumstances (Long commuting time, put in long hours, bad relationships with colleagues, …)					
8. Lack of leisure time/activities (Time to do a hobby, to travel, …)					
9. Because my partner went on retirement					
10. Because a lot of other people from my surroundings went on (early) retirement					
11. Because I had care assignements (take care of another older person, my partner, one of my children, grandchild, …)					
12. I was unemployed for a while (out of work/out of a job					
13. Because I had reached the legal age of retirement/pensionable age					

83. To what extent do you feel that one of the following aspects is lacking in your life now you are retired? (please tick all appropriate items)

1= Not very much
2= Not much
3= Neutral
4= Much
5= Very much

	1	2	3	4	5
1. Professional duties					
2. The daily routine					
3. The difference between my nett wages/salary and my pension					
4. The feeling of being usefull					
5. Contact/relationships with colleagues					
6. Contact with cutomers and business partners					

Thank you very much for cooperating!

Chapter 3 : Access to care of frail community-dwelling older adults in Belgium: a qualitative study

Abstract

Aim

This paper aims to identify barriers frail community-dwelling older adults experience regarding access to formal care and support services.

Background

Universal access to healthcare has been set by the World Health Organisation (WHO) as a main goal for the post-2015 development agenda. Nevertheless, regarding access to care, particular attention has to be paid to so-called vulnerable groups, such as (frail) older adults.

Methods

Both inductive and deductive content analysis were performed on 22 individual interviews with frail community-dwelling older adults who indicated they lacked care and support. The coding scheme was generated from the conceptual framework '6 A's of access to care and support' (referring to work of Penchansky and Thomas, 1981; Wyszewianski, 2002; Saurman, 2016) and applied on the transcripts.

Findings

Results indicate that (despite all policy measures) access to a broad spectrum of care and support services remains a challenge for older people in Belgium. The respondents' barriers concern: 'affordability' referring to a lot of Belgian older adults having limited pensions, 'accessibility' going beyond geographical accessibility but also concerning waiting lists, 'availability' referring to the lack of having someone around, 'adequacy' addressing the insufficiency of motivated staff, the absence of trust in care providers influencing 'acceptability' and 'awareness' referring to limited health literacy.

The discussion develops the argument that in order to make care and support more accessible for people in order to be able to age in place, governments should take measures to overcome these access limitations (e.g. by automatic entitlements) and should take into account a broad description of access. Also, a seventh barrier (a seventh A) within the results, namely 'ageism', was discovered.

Keywords: accessibility; care and support; elderly; frailty; qualitative research

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3.1. Introduction

The World Health Organisation (WHO) pointed out universal access (i.e. the absence of sociocultural, organisational, economical, geographical and gender-related barriers) to healthcare as an overarching goal for health in the post-2015 development agenda (Evans, Hsu and Boerma, 2013; Marziale, 2016). This is recognised by the United Nations Sustainable Development Goals by which all of its United Nations Member States have agreed to try to achieve universal health coverage (i.e. the capacity of health systems to respond to the populations' needs at any care level, without causing financial damage) by 2030 (WHO, 2018). Universal health coverage includes financial risk protection, access to quality essential healthcare services and access to safe, effective, quality and affordable essential medicines and vaccines for all (WHO, 2018). Regarding to health, and particularly access to healthcare, attention must be paid to so-called vulnerable groups such as homeless people, newly-arrived immigrants, sex workers, drug users, but also frail older adults (Rijksinstituut voor Ziekte- en Invaliditeitsverzekering, 2014; Rowe, Fulmer and Fried, 2016). Frailty is a common phenomenon in community-dwelling older adults that is often used in research as a (clinical) phenotype (Fried et al., 2001) or an accumulation of health deficits (Rockwood et al., 1994; Etman et al., 2012). More recently, multidimensional approaches have defined frailty as 'a dynamic state that affects an individual who experiences losses in one or more domains (physical, psychological, social, and more recently, also environmental)' (De Witte et al., 2013). Also different researchers point to the necessity to operationalise frailty as a multidimensional and dynamic concept that considers the complex interplay of physical, cognitive, psychological, social and environmental factors (Bergman et al, 2007; Armstrong et al., 2010; De Witte et al., 2013). The word frailty has a stigma attached pointing towards losses and decline. However**,** frailty has not solely negative consequences in daily life, especially when the right care and support is present. Besides measuring the deficits of frailty, there is also a need to take into account the strengths and resources of older adults (Buntinx et al., 2004). This paper aims to identify barriers frail community-dwelling older adults experience regarding access to formal care and support.

Research on access to health services appears particularly important with the rising proportion of older adults. International research often associates barriers affecting access to healthcare for older adults with the lack of health insurance (Fitzpatrick et al., 2004; Thorpe et al., 2011) or is about specific populations and conditions (e.g. dental care, people facing chronic conditions, people living in rural areas, etc.) (White et al., 2002; Goins et al., 2005; Wallace and Guitérrez, 2005). In Belgium, insurance status is a minor problem, because health insurance is nationally organised and compulsory. Everyone living and/or working in Belgium is required to take an insurance in the event of illness or indemnity by the membership of a health insurance fund (Belgium.be, 2018). Care policy in Belgium is both a responsibility of the federal authorities and federated entities (regions and communities). The federal authorities are mainly

responsible for the regulation and financing of the compulsory health insurance while the federated entities are in charge of health promotion and prevention; different aspects of community care and support services (family aids, cleaning aids, meals on wheels; etc.) and the coordination and collaboration in primary health care and palliative care. To facilitate cooperation between the federal authorities and the federated entities, interministerial conferences are regularly organised (Gerkens and Merkur, 2010; Dumont, 2015). Nevertheless, several challenges in terms of access to care and support in Belgium remain. While the average level of unmet care needs is rather low (0.1% for high incomes and 5.5% among low incomes in 2013) for Belgian inhabitants, the Organisation for Economic Cooperation and Development (OECD) (2016) states that Belgium shows large inequalities: low-income people more often forgo health examinations due to costs, travelling distance or waiting time, compared to high-income people. Despite universal coverage, on average 8% of Belgian households declared in 2013 that they had to postpone healthcare for financial reasons (e.g. medical care, surgery, dental care, prescribed medicines, mental healthcare, eyeglasses or contact lenses). Moreover, the share of out-of pocket payments (i.e. expenditures covered directly by the patient because healthcare insurance does not cover the full amount) is relatively high in Belgium compared to other European countries (18% of total health expenditures). Among older adults, special attention should be drawn to the accessibility and sustainability of long-term care services (Vrijens et al., 2015).

Access to care however is more than being able to pay for care or support expenditures. Already more than 30 years ago, Penchansky and Thomas (1981) published an article in this area entitled “The concept of access: Definition and Relation to Consumer Satisfaction”. Nevertheless, this framework is still commonly used, not only concerning access to healthcare (Clark and Coffee, 2011; Derose, Gresenz and Ringel, 2011; Levesque, Harris and Russell, 2013), but also in a broader context of access to services (United Nations Educational, Scientific and Cultural Organisation, 2013), for example to discover access barriers to healthy food (Usher, 2015; Zhang, 2017), access to energy security (Cherp and Jewell, 2014) and access to education (Lee, 2016). Also, recent research of Saurman (2016) has re-evaluated, improved and extended Penchansky and Thomas' framework to the actual context. Penchansky and Thomas (1981, p. 1) describe access as ‘a general concept that summarises a set of more specific dimensions describing the fit between the patient and the healthcare system’. These specific dimensions are the five A’s (affordability; availability; accessibility; adequacy (or accommodation) and acceptability) of access to care. As the framework already dates from 1981, the definition given to the five A’s seems dated and complex. In a more recent editorial column titled “Access to Care: Remembering Old Lessons”, Wyszewianski (2002, p. 1441) gave an up-to-dated description connecting with the current society. He defines the five A’s of access as follows:

1. *‘Affordability* is determined by how the provider’s charges relate to the client’s ability and willingness to pay for services’;

2. *'Availability* measures the extent to which the provider has the requisite resources, such as personnel and technology, to meet the needs of the client';
3. *'Accessibility* refers to geographic accessibility, which is determined by how easily the client can physically reach the provider's location';
4. *'Adequacy (or accommodation)* reflects the extent to which the provider's operation is organised in ways that meet the constraints and preferences of the client. Of greatest concern are hours of operation, how telephone communications are handled and the client's ability to receive care without prior appointments';
5. *'Acceptability* captures the extent to which the client is comfortable with the more immutable characteristics of the provider, and vice versa. These characteristics include the age, sex, social class, and ethnicity of the provider (and of the client), as well as the diagnosis and type of coverage of the client'.

Recently, Saurman (2016, p. 37) proposed a sixth dimension to further develop the framework of access of Penchansky and Thomas, namely awareness:

6. *'Awareness* refers to effective communication and information strategies with relevant users (clinicians, patients, the broader community)'.

Saurman links the concept of awareness to the challenge of health literacy. 'Health literacy' is defined as the 'degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions' (Parker and Ratzan, 2010:20). Low literacy may cause health disparities, especially among older adults inadequate health literacy is associated with poorer physical and mental health (Wolf, Gazmararian and Baker, 2005; Saha, 2006; Chesser et al., 2016). Recent studies also revealed that advanced age might result in a significant increase in the prevalence of inadequate health literacy which demands for a tailored approach (Zamora and Clingerman, 2011; Manofo and Wong, 2012).

In this study, we focus on one of the above defined vulnerable groups deserving special attention, namely community-dwelling older adults. Despite being a major policy goal, the challenge of access to care among community-dwelling older adults is still majorly understudied, especially using a structured framework (Evans, Hsu and Boerma, 2013). As older people are major consumers of healthcare, the growing proportion of older people in European populations does present some challenges concerning their access to the healthcare and welfare system as well to the affordability for providing institutions (WHO, 2014).

Facing the mentioned research gaps, this research is handling challenges of general access to care and support of frail community-dwelling older adults using a broad and comprehensive framework. In doing so,

the following central research question is addressed: which barriers do frail, community-dwelling older adults experience to access formal care and support services? To detect these barriers, we use the five A's of access to care from Penchansky and Thomas (1981) as they are described by Wyszewianski (2002) and the sixth A (awareness) as added by Saurman (2016) together resulting in a new framework of 'six A's of access to care and support'.

3.2. Methods

3.2.1. Data collection

For this paper, data collected within the Detection, Support and Care for older people – Prevention and Empowerment (D-SCOPE) project were used. The D-SCOPE project is a four-year research project (2015-2018) that investigates strategies for proactive detection of potentially frail, community-dwelling older people, in order to guide them towards adequate support and/or care with a focus on empowerment. The general aim of the second phase of the D-SCOPE-research, where this paper is taking part in, was to gain information concerning the experiences and meaning of older people on frailty and their possibility to age in place. The Ethical Commission Human Sciences of the Vrije Universiteit Brussel approved the study (file number ECHW_031). Older people were asked to sign an informed consent agreement. In case they were not capable of signing this document, a family member or another legal representative was allowed to sign it on their behalf, as stipulated by the Belgian civil code. Respondents were informed about the voluntary nature of their involvement in the study, their right to refuse to answer, and the privacy of their responses. Also, respondents had the right not to participate in the study and to withdraw their consent at any time without negative consequences. Refusal to consent led to exclusion of the study.

The overall data collection within the second phase of the D-SCOPE research comprised data of 121 community-dwelling older adults (60+) in the Dutch-speaking part of Belgium and in Brussels. These interviews took place in participants' homes or in the local service centre. Data were collected between November 2015 and March 2016. Respondents were purposively sampled based on risk profiles for multidimensional frailty, which included age, gender, marital status, level of education, household income, whether the respondent had moved in the previous ten years and country of birth (Dury et al., 2017). Hospitalisation and any state that may interfere with a good understanding of the questions (being too sick to participate in the interview, etc.) (according to the participant or an informal caregiver) or also the inability to provide adequate answers during the face-to-face interviews (as noted by the interviewer) were exclusion criteria. The presence of dementia was also an exclusion criterion. The current paper reports on a selection of 22 face-to-face interviews.

3.2.2. Interview scheme

Nine trained researchers conducted a quantitative questionnaire and a qualitative semi-structured interview. The quantitative questionnaire comprised questions related to socio-demographic and socio-economic characteristics and the Comprehensive Frailty Assessment Instrument (CFAI) (De Witte et al., 2013), which is a self-administered instrument and measures four domains of frailty from a holistic approach. The CFAI contains 23 indicators and demonstrates a high overall internal consistency and high consistency of its scales, thus supporting the validity and reliability of the instrument and highlighting to the multidimensionality of frailty. The CFAI has been proven to be internally consistent, with a Cronbach's α of .812 that explains 63.6% of the variance in frailty (De Witte et al., 2013). For the physical domain of frailty, the respondent's general physical health was assessed using four items, such as whether they could walk up a hill or stairs. The psychological domain was captured by measuring mood-disorders and emotional loneliness (eight items, e.g. feeling unhappy or depressed). The social domain of frailty was evaluated by older people's social loneliness (three items, e.g. "I feel an emptiness around me") and their potential social support network (ten items e.g., partner, children, neighbours). Finally, environmental frailty was assessed by propositions regarding the suitability of the physical housing environment (five items e.g., the house is in a bad state). Cognitive frailty was originally not included in the original CFAI. Four questions were added to the CFAI to assess subjective cognitive frailty, which resulted in the CFAI-plus (keeping good psychometric qualities) (De Roeck et al, 2018) Finally, the sufficiency of care and support was assessed with a one-item question, e.g.: "On a scale from zero to ten, to what extent do you feel that the care and support you receive is sufficient?". Scores ranged from zero (bad) to ten (excellent) on a Numerical Rating Scale. To assess the significance of that score each answer was followed by a question to indicate whether the participant perceived the score as poor, average or good.

After the quantitative part, the same researchers held a semi-structured face-to-face interview with open-ended questions with the participants. This was the main part of the second phase of the D-SCOPE research. The topic list consisted of four main questions: (a) "How do you experience frailty and what does frailty mean to you?"; (b) "How do you experience frailty has an effect on your quality of life, care and support, meaning in life, and to what extent do you still have control over the things happening in your life?"; (c) "What should an older person do, have or need to maintain his/her quality of life when becoming frail?"; (d) "What were the highlights and what were the low points in your life during the past year, did changes occur? And how do you feel about the future?". The topic list was developed within the D-SCOPE research group, which consists of researchers specialised in gerontology and/or frailty and representing several disciplines (e.g. old age medicine, psychology, educational sciences, etc.). A panel of experts approved all questions, indicating for content validity in the interview (Landsheer and Boeije, 2010). The expert panel consisted of two neurologists specialised in dementia, a psychologist specialised in neuropsychology and

dementia, five adult educational scientists specialised in social gerontology, three general practitioners specialised in frailty in later life, and two social gerontologists specialised in public health. Researchers that conducted the interviews received training and several scenarios were developed in order to address potential difficulties (e.g., difficulties in understanding the concept frailty) (Dury et al., 2018). All researchers also received a list of definitions explaining the terms used in the questionnaire. This list was used when participants didn't have a clear comprehension of the questions. All interviews were held in the language of the respondents' choice. Most of the interviews were conducted in Dutch or French by one of the researchers. In order to achieve maximum participation of participants who did not speak those languages, an interpreter attended the interviews when necessary. The interviews were digitally recorded (Audacity) with the participant's permission, and afterwards verbatim transcribed. Regarding the interviews in the presence of an interpreter, only the answers as translated by the interpreter were transcribed. All data were anonymised and analysed according to the rules of the Belgian Privacy Commission (Law of 7 May 2004).

3.2.3. Participants

The qualitative data used in this study consist of anonymised transcripts of 22 individual interviews (with a mean time of 1h 14m 51s) (see table 5 for the characteristics of the participants). In the larger D-SCOPE research, 121 older adults at risk for frailty (based on risk profiles for frailty; Dury et al., 2017) were interviewed. A purposive sampling procedure was used to identify, recruit and select potentially frail, community-dwelling older adults. Five homecare organisations recruited 64 respondents from their clients and 57 respondents were recruited by snowball sampling. Based on the results of the CFAI-plus, older adults were grouped into 1) not-to-low frail, 2) low-to-medium frail, and 3) medium-to-high frail, for each domain of frailty (De Roeck et al., 2018). The CFAI-plus was part of the quantitative questionnaire administered to the participants before conducting the qualitative interviews. Another question within the quantitative questionnaire assessed the sufficiency of care and support with a one-item question, e.g.: "On a scale from zero to ten, to what extent do you feel that the care and support you receive is sufficient?". The objective of the present study is to explore how frail, older adults experience barriers in accessing formal care and support services. Therefore, we selected the interviews of participants who were medium to highly frail according to the CFAI-plus and reported to be in need of care and support at the moment of the interview (i.e. having a score lower than eight (=median of the total sample) on the question: "On a scale from zero to ten, to what extent do you feel that the care and support you receive is sufficient?"). This resulted in 22 respondents.

The average age of the participants was 77.8 years (range 61 – 94 years). A majority of the participants were female (N=12). Three participants were married and 12 were widowed. Three of them had a migration background (i.e. born in a different country than Belgium).

Table 5. Characteristics of the participants (N = 22)

Characteristics		Total (N)	%
Age	77.8 years (range 61 – 94 years)		
Gender	Male	10	46.5
	Female	12	54.5
Marital status	Married	3	13.6
	Never married	2	9.1
	Divorced	5	22.8
	Widowed	12	54.5
Migration background	Yes	3	13.6
Severe frail on which type of frailty	Physical	10	
	Cognitive	16	
	Psychological	10	
	Social	7	
	Environmental	6	
Number of domains severe frail	1 domain	8	36.4
	2 domains	6	27.2
	3 domains	3	13.7
	4 domains	4	18.2
	5 domains	1	4.5

3.2.4. Data analysis

In this study, we performed a thematic content analysis on the data using both deductive, concept driven coding, and inductive, data driven coding (Elo et al., 2014; Fereday and Muir-Cochrane, 2006; Hamad et al., 2016). First, within the deductive approach, we used the six A's of access to care as sensitizing concepts (Moula, 2017), in order to test if the existing framework that has been used in previous research several times fits in the context of community-dwelling older adults accessing formal care and support services (Vaismoradi, Turunen and Bondas, 2013). For the deductive coding, a codebook was developed using the six A's of access to care (Penchansky and Thomas, 1981; Wyszewianski, 2002; Saurman, 2016) (see above) as the main labels. Following on this, we performed the inductive coding, seeking to add dimensions to the six A's and give meaning to these labels by creating sublabels. All interviews were coded and analysed using the computer software program MAXQDA (VERBI Software, Berlin, Germany), which is a content analysis package with a good interpretive style (Kuş Saillard, 2011). The 22 trancripts were analysed by the principal researcher and coded using MAXQDA. These codes were evaluated and discussed with the co-researchers and refined until consensus was reached.

3.3. Results

The interviews revealed a whole range of barriers concerning the access to a broad spectrum of formal care and support services for community-dwelling older people. These problems varied from lack of financial resources to mobility problems, but also inappropriate organisation of services and lack of information. We analysed the respondents' stories using the framework of Penchansky and Thomas (1981) as it was adapted and actualised by Wyszewianski (2002) and Saurman (2016), nevertheless, an additional 7th barrier outside the framework was mentioned by the respondents, namely 'ageism'. Notwithstanding several barriers were perceived by older respondents, some older adults also mentioned positive experiences regarding different aspects of access to care and support.

3.3.1. Affordability

'Affordability is determined by how the provider's charges relate to the client's ability and willingness to pay for services' (Wyszewianski, 2002, p. 1441) and was often quoted as a barrier among the respondents. One of the problems respondents referred to was the combination of small pensions and the increasing cost of living with care and support needs. These small pensions impeded some of our respondents for example to move to a more adapted housing (a retirement flat, etc.) or to carry out the necessary modifications in their home.

"I only became a cleaning lady after school. As a consequence, I have the minimum pension. I can't afford to pay €700 or €800 rent with my pension of €1100. Otherwise I would already be living in Evergem (i.e. where her sister lives in social housing) for a long time. That is what impedes me." (woman, 69y, divorced)

"I once took information for a retirement flat, which now often has several home automation systems. They said hiring them would cost me approximately €19. I thought €19 per month, that is something I can afford. But then my son had a look at the papers and asked me if I was going to pay almost €600 per month to use these home automation systems. It seemed that the price was €19 per day and not per month. That immediately changed my opinion." (woman, 80y, widowed)

Conversely, an older man also mentioned the positive results of being able to move to a social apartment last year: *"Since I'm living here, I have to pay much less for the rent and for the heating." (man, 66y, divorced)*

Another barrier several respondents experienced, was the price of housing modifications, especially when the government is not subsidising.

"The only thing I ever asked for was a stair lift. You can have that, but the government only contributes until the age of 65. When older than 65, you need to pay for it yourself. But who needs a stair lift before the age of 65? Most of the people will only need it after the age of 65. And then they don't contribute anymore. That doesn't make sense." (man, 72y, widowed)

Respondents also mentioned their 'lack of willingness to pay' for a service as an obstacle.

"And for support, the financial side plays a role. I have savings, but I don't like to use them. I prefer to support my children and grandchildren. A part of me says: X (respondent), you saved the money, use it. Another part of me says no." (woman, 80y, widowed).

3.3.2. Availability

'Availability measures the extent to which the provider has the requisite resources, such as personnel and technology, to meet the needs of the client' (Wyszewianski, 2002, p. 1441), but also refers to lack of informal care and support. Availability was regularly mentioned as a barrier.

This lack of availability of professional care services was regularly stated. A 61-year old Turkish woman addressed the lack of availability of a professional caregiver to help her managing her disease, because she cannot count all the time on her informal network:

"(Interpreter of respondent): She doesn't receive professional care. She has to do a blood test by herself. She takes her medication by herself. She can't go with her eldest daughter because she is busy herself with her husband and her children. From time to time she stays with her youngest daughter, but that's a single mother." (woman, 61y, widowed)

On the other hand, a woman mentioned that she was not in need of help at the moment, but when it would be case, she would have the possibility to apply for it: *"I don't need any help yet. But when this would be the case, I could ask the Foyer (i.e. social housing company) to come and clean my house and my windows. There are possibilities." (woman, 70y, widowed).*

In addition to the lack of formal care also the lack of informal care was mentioned. Regarding informal care, respondents often mentioned the lack of availability of someone in their family or social network to help them when they would become dependent, or in case of an emergency. For example, a 70 year old widower stated how it worried him to live alone in his house:

"The lack of having someone around me. That's the problem. I sit here in the evening and I go to sleep. That's OK. But what do I have to do when I can't climb the stairs anymore? Stay downstairs? What do I have to do then? That's what I'm thinking about." (man, 70y, widowed)

Regularly, the presence of non-family members as informal caregivers was mentioned. An older man especially mentioned (in a positive sense) the presence of a friend (as informal caregiver) he could rely on for any kind of assistance: *"She really takes good care of me. She does the shopping and always brings nice things. She even takes my bank card. I completely trust her. She also has a key of my apartment. There are moments that I can't stand up and then she enters with the key." (man, 81y, widowed).* Another woman

testified about having her neighbour around when being in need: *"Yes, my neighbour is really close. I don't have to call her to come around. I don't want to call my sister, she's too stifling." (woman, 70y, widowed)*

3.3.3. Accessibility

'Accessibility refers to geographic accessibility, which is determined by how easily the client can physically reach the provider's location' (Wyszewianski, 2002, p. 1441) or how easily the provider can reach the client. In this context, some respondents quoted that accessibility of services within a feasible distance was a problem.

In this context, a lot of respondents stated their lack of mobility.

"My receipts for the healthcare fund have to be put in an envelope in a letter box at the Hopmarkt in Aalst (i.e. the centre of the city). So, I have to ask someone to take my notes when they go to the city. And when I need information, I have to call a central telephone number in Ghent (i.e. a city 40km away)." (woman, 80y, widowed)

Besides the distance of services, respondents also considered their own mobility as important regarding accessibility of services. Several people for instance were concerned about losing their car or driving license as it guaranteed their independence and was needed to get to services.

"When I get involved in a car accident right now, they (i.e. the police) will start asking questions: sir, can you still see enough? And the insurance company, will they still give me an insurance? This scares me a lot. Because when they take my car, I have a big problem. Then I would be stuck. Even taking my wife to the doctor would be a problem." (man, 81y, married)

However, respondents were not only talking about geographical accessibility, but also other issues concerning accessibility such as waiting lists.

"I took information for a cleaning lady with service vouchers, but there is a waiting list of six months. I decided to let it go. It is always the same story, when you ask something, you end up on a waiting list." (man, 72y, widowed)

3.3.4. Adequacy (or accommodation)

'Adequacy (or accommodation) reflects the extent to which the provider's operation is organised in ways that meet the constraints and preferences of the client. Of greatest concern are hours of operation, how telephone communications are handled and the client's ability to receive care without prior appointments' (Wyszewianski, 2002, p. 1441). Respondents mentioned several inadequacies within formal care services (hospitals, formal home care) such as lack of motivation among staff.

Several older respondents found it important that formal care organisations were well organised and hired well educated and motivated staff: *"I think that the directors or people responsible have to motivate their staff. 50% or more of the people that work over there lack motivation. Especially in the care sector, there has to be motivation. I am aware it is a special profession to wash and take care of older people." (woman, 80y, widowed)*

Another concern often mentioned were the hours of operation (and more specifically the pace of working). This concern could reflect an organisational complaint or be focused on the individual professional behaviour.

"Every 14 days, they came for 20 or 25 minutes (home carers). What can they do during that time?" (man, 78y, widowed)

Also the (lack of) quality of services was mentioned. Older people expressed they lacked personal contact with the professional caregiver.

"The caregiving is off less quality than before. I have the feeling we became more of a number." (woman, 89y, never married)

3.3.5. Acceptability

'Acceptability captures the extent to which the client is comfortable with the more immutable characteristics of the provider, and vice versa. These characteristics include the age, sex, social class, and ethnicity of the provider (and of the client), as well as the diagnosis and type of coverage of the client' (Wyszewianski, 2002, p. 1441).

Regarding 'acceptability' our respondents indicated that they do not always trust the care providers and consequently do not accept the care: *"You don't know if you can trust them. People that are doing that kind of work never studied." (man, 81y, married)*

Some specific care tasks were more difficult to accept, as they were more in the personal sphere. In this case the diffidence to be washed by a professional caregiver was a concern raised by a 78-years old divorced woman: *"In the beginning, I found it difficult to be washed. In that time, I was still in much better physical condition than now." (woman, 78y, divorced)*

3.3.6. Awareness

'Awareness refers to effective communication and information strategies with relevant users (clinicians, patients, the broader community), including consideration of context and health literacy' (Saurman, 2016, p. 37). Concerning the aspect communication and information, respondents mostly talked about the difficulties in getting appropriate information (about financial compensations, reductions, etc.): *"Like financial things for example. The health insurance fund gives some compensations, you see, … There are some small compensations that I don't receive. I don't know how to do the necessary things, I need to find a social assistant…" (woman, 89y, divorced)*

Also the need for health literacy in finding the appropriate information was mentioned by respondents.

"(Daughter of respondent): All the papers you have to send to the right place to get a small contribution. She (her mother) could never do that. That is why I am doing that for her. When the invoice of the hospital comes, she will never be able to understand that. So I am doing that for her as well. Also the papers for the insurance, it's me who has to deal with it." (woman, 94y, widowed)

3.3.7. Ageism

Older adults also reported experiences with 'ageism' (i.e. stereotyping and discrimination against individuals and groups on the basis of their age) as a barrier. An older man complained about the daughter of his partner, because she (i.e. the daughter) wanted to take over everything: *"Last year, we really had a problem with her (i.e. the daughter of his partner), she wanted to do everything (i.e. the planning of their trip, etc.). Now I said: we'll do everything on our own, because I was sick of it. Children always think they know everything better. We can deal with it on our own." (man, 84y, divorced)*

3.3.8. Different aspects interfering/relating

Within the stories of older respondents, there were also experiences of different aspects of access interfering or relating to each other. There was the story of an older man who said that his recent moving to a social apartment (after several years) not only had a possible influence on his financial situation (i.e. 'affordability' because of a cheaper rent) but also on his physical 'accessibility' for care providers, as well as his own mobility: *"I live on the ground floor now, this means that the social service of the municipality can enter to pick me up." (man, 66y, widowed)*

Another man told about the long waiting list for his electric mobility scooter (because of a long administrative procedure within the healthcare fund) which is interfering the physical 'accessibility' to providers and services: *"I decided to apply for an electric mobility scooter so I can drive around a little more, have contact. But the application for a scooter goes through the healthcare fund, like for a wheelchair. I'm already waiting for six months now and they are still not finished." (man, 79y, divorced)*

3.4. Discussion

This study reports on qualitative experiences concerning access to care and support for frail community-dwelling older adults, following the framework of Penchansky and Thomas (1981) as adapted and actualised by Wyszewianski (2002) and Saurman (2016) resulting in six A's of access to care and support: accessibility; affordability; availability; acceptability; adequacy (or accommodation) and awareness. The research question defined for this study was the following: which barriers do frail, community-dwelling older adults perceive to access formal care and support services?

Our study shows that this framework can be confidently applied to detect concerns of access to formal care and support for frail older adults. It brings to attention a very broad approach of care and support going beyond pure medical care. *Affordability* of services was mentioned as an important barrier. Although Belgium is a prosperous country, pensions in Belgium are rather low compared to other EU countries. Stronger, the statutory pensions in Belgium are of the lowest of all European member states (OECD, 2011). Although research indicates that Belgian older people are 'asset-rich but income poor' (i.e. a relatively high percentage of Belgian older people own their house) (Smetcoren, 2016); our interviews showed that the affordability of care often has to do with the concern of care support by adapted housing. In this scope, the high cost of several essential extras that have to be paid (for example home automation systems in retirement flats, or housing adaptations like the stair elevator) clearly influence affordability. Like the majority of older people, our respondents indicated they prefer to live in their own house as long as possible (Wiles et al., 2011). A mentioned barrier to be able to 'age in place' is the high cost of housing modifications, for which the government is not or only a limited percentage contributing. This research also shows that affordability can be interconnected with *accessibility*, for example when not meeting conditions applied by local governments to enter social housing or in a positive way when moving to a cheaper adapted apartment on the ground made it easier for providers to physically reach the client. The interviews clearly showed that improving one barrier might have a positive impact on (an)other barrier(s) as well. We also noticed concerns about the *availability* of care and support services when older people would become more dependent and in need of it, both in terms of professionals and informal carers. Recent research concluded that 3.8 % of community-dwelling older adults who reported to be in need of care and support, did not receive this (Fret et al., 2017). Respondents also indicated they lacked informal care. Despite growing policy attention, the informal care network also has its limitations (e.g. children having a busy career, a daughter being a single parent). This is in line with research of Smetcoren et al. (2018) in which some participants mentioned the impact of not having children, while others talked about barriers to get help from children such as distance.

Concerning *accessibility,* our respondents made clear that accessibility goes beyond geographic accessibility as it is described by Wyszewianski (2002). It also concerns for example waiting lists that limit the

accessibility of services. This is in line with research results of Bleustein et al. (2014) about waiting times in healthcare. Within the theme of *adequacy (or accommodation)* respondents complained about lack of motivation or lack of time of professional caregivers. These concerns are shared in recent research by Kilgore (2016) about home care staffing and patient satisfaction. By using the mentioned framework, it became clear that it is important to take into account the often-neglected individual characteristics of the client and the provider that influence *acceptability* (i.e. socio-economic characteristics, trust) (Wyszewianski, 2002). Within *awareness*, the greatest concern was the complexity of finding appropriate information or the lack of *health literacy* of older adults. Although research clearly shows that Belgian healthcare is performant and of good quality (Vrijens et al., 2015), the organisation is rather complex and shredded (especially after the sixth Belgian Reform of the State of 2014) (Schokkaert, 2016). It was particularly clear that the aspect of awareness influenced the access to care and support for our respondents, especially for those with limited health literacy. We also discovered a 7th barrier (a 7th A) within the results, namely *ageism* which are stereotypes towards older adults that are described in literature as a barrier for qualitative elderly care (Kane and Kane, 2005; Reyna et al.; 2007).

3.4.1. Limitations and future research

This study contains some limitations. First, we used interviews which were conducted not solely in the context of this paper and that have been collected to answer different research questions. In order to overcome this limitation, the quality of the data has been assessed through pre-analyses and discussion, and the investigators explored if the data fitted appropriately the research questions (Hox and Boeije, 2005). Second, the framework we used is an adapted and actualised version of the original framework of Penchansky and Thomas (1981) to which the aspect of awareness by Emily Saurman (2016) was added. This might be one of the first studies that has used this new framework within the context of access to care and support of frail community-dwelling older adults. Although we could identify some interesting results and discovered an additional barrier within the data (ageism), further research should be conducted to determine whether all barriers community-dwelling older adults experience were covered. Third, it would be particularly interesting to explore if any barriers were more important to those with different types of frailty, or who were frail across a greater number of domains as we focused In this paper on a general population of frail community-dwelling older adults. Future research could provide some more evidence.

3.5. Conclusion and policy implications

Within the scope of frail community-dwelling older adults, this study brings to attention that (despite all policy measures) access to a broad spectrum of care and support services remains a challenge for our ageing society. The respondents' barriers to access care and support go beyond solely medical services; they also involve the availability of having someone around when they are in need, waiting lists, the price of housing

modifications or home automation systems, etc. This might be a challenge for our society with enhancing policy attention for community based care and support where more care and support tasks are entitled to local actors (Dury, 2018; Smetcoren et al., 2018). Although the concept of access goes much further than affordability, the financial aspect was often mentioned referring to a lot of Belgian older adults having limited resources and low pensions (Litwin and Sapir, 2009) and seems to remain the most important barrier within Penchansky and Thomas framework. The aspect of affordability seems clearly *interconnected* with awareness and accessibility, referring to the complex organisation of the Belgian State and difficult procedures to get access to financial compensations. A system of automatic entitlement might give an answer to that (Moffatt and Scambler, 2008). In recent years, a project to proactively entitle a higher reimbursement status for medical care to people with low incomes already showed promising results and pointed out that automatic entitlement might be an effective strategy to improve the access to different kind of services (Goedemé et al., 2017). Another recent measure (since 2012) that provided good results was to give the possibility to low-income and vulnerable Belgian inhabitants to consult their general practitioner for one euro (the rest of the fee is paid directly to the general practitioner by the healthcare fund). It might be effective to give the possibility to other caregivers to apply this system on their patients (CM, 2018). The results also point to the complex and illogical Belgian care legislation or complex procedures, especially for older adults with limited health literacy. The impossibility to get an official recognition and the necessary contributions (for housing adaptations, etc.) when becoming disabled after the age of 65 is just one example. This should be a permanent point of attention for politicians to keep in mind. This paper also made clear that the framework of Penchansky and Thomas (1981) as adapted and actualised by Wyszewianski (2002) and Saurman (2016) is also applicable to detect barriers in access to a broad range of formal care and support services (going beyond solely medical care) for frail community-dwelling older adults.

References

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

Bergman, H., Ferrucci, L., Guralnik, J., Hogan, D. B., Hummel, S., Karunananthan, S. and Wolfson, C. (2007). Frailty: an emerging research and clinical paradigm - issues and controversies. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *62*(7), 731-737.

Belgium.be. (2018). *Healthcare costs*. [online] Available at: https://www.belgium.be/en/health/healthcare_costs [Accessed 12 Apr. 2017].

Bleustein, C., Rothschild, D.B., Valen, A., Valatis, E., Schweitzer, L. and Jones, R. (2014). Wait times, patient satisfaction scores, and the perception of care. *The American Journal of Managed Care*, 20, 393–400.

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

Cherp, A. and Jewell, J. (2014). The concept of energy security: Beyond the four As. *Energy Policy*, *75*, 415-421.

Chesser, A., Keene Woods, N., Smothers, K. and Rogers, N. (2016). Health Literacy and Older Adults. *Gerontology and Geriatric Medicine*, 2, 1-13.

Clark, R. and Coffee, N. (2011) Why Measuring Accessibility is Important for Public Health: A Review from the Cardiac ARIA Project. *Public Health Bulletin of South Australia*, *8*(1), 3-8.

CM. *Huisartsen: tarieven raadplegingen 2018. [General practitioners and consults 2018]* [online] Available at: https://www.cm.be/diensten-en-voordelen/ziekte-en-behandeling/terugbetalingen-behandelingen/huisartsen/raadplegingen [Accessed 30 Aug. 2018].

Derose, K., Gresenz, C. and Ringel, J. (2011). Understanding Disparities In Health Care Access--And Reducing Them--Through A Focus On Public Health. *Health Affairs*, 30(10), 1844-1851.

De Roeck, E., Dury, S., De Witte, N., De Donder, L., Bjerke, M., de Deyn, P., Engelborghs, S. and Dierckx, E. (2018). CFAI-Plus: Adding Cognitive Frailty as a New Domain to the Comprehensive Frailty Assessment Instrument. *The International Journal of Geriatric Psychiatry,* 33(7), 941-947.

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

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Schols, J., & Verté, D. (2013). The comprehensive frailty assessment instrument: development, validity and reliability. *Geriatric Nursing*, *34*(4), 274-281.

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Verte, D. and Schols, J. (2013). Validation of the comprehensive frailty assessment instrument against the Tilburg frailty indicator. *European Geriatric Medicine,* 4(4), 248–254.

Dury, S., De Roeck, E., Duppen, D., Fret, B., Hoeyberghs, L., Lambotte, D., Van der Elst, M., van der Vorst, A., Schols, J., Kempen, G., Rixt Zijlstra, G., De Lepeleire, J., Schoenmakers, B., Kardol, T., De Witte, N., Verté, D., De Donder, L., De Deyn, P., Engelborghs, S., Smetcoren, A. and Dierckx, E. (2016). Identifying frailty risk profiles of home-dwelling older people: focus on sociodemographic and socioeconomic characteristics. *Aging & Mental Health*, 21(10), 1031-1039.

Dury, S. (2018). Dynamics in motivations and reasons to quit in a Care Bank: a qualitative study in Belgium. *European Journal of Ageing*, 1-10.

Dumont, D. (2015). De sociale zekerheid en de zesde staatshervorming: voorgeschiedenis en algemene beschouwingen [Social security and the sixth Reform of the State: history and general considerations]. *Belgisch Tijdschrift voor Sociale Zekerheid 15(2),* 175-228.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K. and Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *Sage Open*, 4(1), 1-10.

Etman, A., Burdorf, A., Van der Cammen, T, Mackenbach, J. P and Van Lenthe, F. J. (2012). Socio-demographic determinants of worsening in frailty among community-dwelling older people in 11 European countries. *J epidemiol community health*, *66*(12), 1116-1121.

Evans, D., Hsu, J. and Boerma, T. (2013). Universal health coverage and universal access. *Bulletin of the World Health Organisation*, 91(8), 546-546A.

Fereday, J. and Muir-Cochrane, E. (2006). Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International Journal of Qualitative Methods*, 5, 80-92.

Fitzpatrick, A., Powe, N., Cooper, L., Ives, D. and Robbins, J. (2004). Barriers to Health Care Access Among the Elderly and Who Perceives Them. *American Journal of Public Health*, 94(10), 1788-1794.

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

Fried, L.P., Tangen, C.M., Walston J., Newman, A.B. Hirsch, C., Gottdiener, J., Seeman, T., Tracy, R., Kop, W.J. and McBurnie, M.A. (2001). Frailty in older adults. Evidence for a Phenotype. *The Journals of Gerontology: Series A,* 56(3), 146-156.

Gerkens, S. and Merkur, S. (2010). Belgium: Health system review. *Health systems in transition*, *12*(5), 1-266.

Goedemé, T., Van Gestel, R., Janssens, J., Lefevere, E., Lemkens, R., & De Spiegeleer, T. (2017). De proactieve flux: een succesvolle manier om de opname van de verhoogde tegemoetkoming te verbeteren. [The proactive flux: a successfull way to improve the uptake of the higher reimbursement status]. *CM-Informatie*, (270), 19-25.

Goins, R., Williams, K., Carter, M., Spencer, S. and Solovieva, T. (2005). Perceived Barriers to Health Care Access Among Rural Older Adults: A Qualitative Study. *The Journal of Rural Health*, 21(3), 206-213.

Hamad, E., Savundranayagam, M., Holmes, J., Kinsella, E. and Johnson, A. (2016). Toward a mixed-methods research approach to content analysis in the digital age: the combined content-analysis model and its applications to health care Twitter feeds. *Journal of medical Internet research*, 18(3).

Health policy in Belgium. (2016). [ebook] Paris: Organisation for Economic Cooperation and Development. Available at: http://www.oecd.org/belgium/Health-Policy-in-Belgium-February-2016.pdf [Accessed 12 Apr. 2017].

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

Kane, R. and Kane, R. (2005). Ageism in healthcare and long-term care. *Generations*, *29*(3), 49-54.

Kilgore, L. (2016). Home Care Staffing and Patient Satisfaction. *Home Healthcare Now,* 34*(2),* 115.

Kuş Saillard, E. (2011). Systematic Versus Interpretive Analysis with Two CAQDAS Packages: NVivo and MAXQDA.*Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 12*(1).

Law of 7 May 2004 considering experiments on human beings, *Belgisch Staatsblad,* 18 May 2004.

Landsheer, J. and Boeije, H. (2010). In search of content validity: facet analysis as a qualitative method to improve questionnaire design. *Quality & Quantity*, 44(1), 59-69.

Levesque, J., Harris, M. and Russell, G. (2013). Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health*, 12(1), 18.

Lee, J. (2016). Paying for School Choice: Availability Differences among Local Education Markets. *International Journal of Education Policy and Leadership*,*11*(5), n5.

Litwin, H. and Sapir, E. (2009). Perceived Income Adequacy Among Older Adults in 12 Countries: Findings From the Survey of Health, Ageing, and Retirement in Europe. *The Gerontologist*, 49(3), 397-406.

Manafo, E. and Wong, S. (2012). Health literacy programs for older adults: a systematic literature review. *Health Education Research*, 27(6), 947-960.

Marziale, M. (2016). Universal Access to Health and Universal Health Coverage: Nursing contributions. *Revista Latino-Americana de Enfermagem*, 24(0).

Moffatt, S. and Scambler, G. (2008). Can welfare-rights advice targeted at older people reduce social exclusion?. *Ageing & Society*, 28(6), 875-899.

Moula, A. (2017). Building a Framework for Sensitizing Concepts. In *Brain, School, and Society* (pp. 23-41). Springer: Cham.

Opening new avenues for empowerment: ICTs to access information and knowledge for persons with disabilities. (2013). [ebook] Paris: United Nations Educational, Scientific and Cultural Organisation (UNESCO). Available at: http://unesdoc.unesco.org/images/0021/002197/219767e.pdf [Accessed 12 Apr. 2017].

Parker, R. and Ratzan, S. (2010). Health Literacy: A Second Decade of Distinction for Americans. *Journal of Health Communication*, 15(sup2), 20-33.

Penchansky, R. and Thomas, J. (1981). The Concept of Access: definition and relationship to consumer satisfaction. *Medical Care*, 19(2), 127-140.

Pensions at a glance. Retirement-income Systems in OECD and G20 Countries. (2011). [ebook] Paris. Available at: http://www.keepeek.com/Digital-Asset-Management/oecd/finance-and-investment/pensions-at-a-glance-2011_pension_glance-2011-en#.WiZpQ0ribcs#page5 [Accessed 7 Dec. 2017].

Research for Universal Health Coverage. (2014). [ebook] Luxembourg: World Health Organisation. Available at: http://apps.who.int/iris/bitstream/10665/85761/2/9789240690837_eng.pdf?ua=1 [Accessed 12 Apr. 2017].

Reyna, C., Goodwin, E. J. and Ferrari, J. R. (2007). Older adult stereotypes among care providers in residential care facilities: examining the relationship between contact, education, and ageism. *Journal of Gerontological Nursing*, *33*(2), 50-55.

Rijksinstituut voor Ziekte- en Invaliditeitsverzekering (2014). *White paper on access to care in Belgium.* Brussels: NIHDI et Médecins du Monde.

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

Rowe, J., Fulmer, T. and Fried, L. (2016). Preparing for Better Health and Health Care for an Aging Population. *JAMA*, 316(16), 1643.

Saha, S. (2006). Improving literacy as a means to reducing health disparities. *Journal of General Internal Medicine*, *21*(8), 893-895.

Saurman, E. (2016). Improving access: modifying Penchansky and Thomas's Theory of Access. *Journal of Health Services Research & Policy*, 21(1), 36-39.

Schokkaert, E. (2016). *De gezondheidszorg in evolutie: uitdagingen en keuze. [Healtcare in evolution: challenges and choices].* Koninklijke Vlaamse Academie van België voor Wetenschappen en Kunsten: Brussel.

Smetcoren, A. (2016). *I'm not leaving!? Critical perspectives on 'ageing in place'*. (Published doctoral dissertation Vrije Universiteit Brussel). Brussels: University Press.

Smetcoren, A., De Donder, L., Duppen, D., De Witte, N., Vanmechelen, O. and Verté, D. (2018). Towards an 'active caring community' in Brussels. In: T. Buffel, ed. *Age-friendly cities and communities: A global perspective*, 1st ed. Bristol: Policy Press at the University of Bristol, 97-118.

Thorpe, J., Thorpe, C., Kennelty, K. and Pandhi, N. (2011). Patterns of perceived barriers to medical care in older adults: a latent class analysis. *BMC Health Services Research*, 11(1).

Usher, K. M. (2015). Valuing all knowledges through an expanded definition of access. *Journal of Agriculture, Food Systems, and Community Development*, *5*(4), 109-114.

Vaismoradi, M., Turunen, H. and Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15(3), 398-405.

Vrijens F., Renard F., Camberlin C., Desomer A., Dubois C., Jonckheer P., Van den Heede K., Van de Voorde C., Walckiers D., Léonard C. and Meeus P. *Performance of the Belgian Health System - Report 2015*. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE). 2016. KCE Reports 259C.

Wallace, S. and Gutiérrez, V. (2005). Equity of access to health care for older adults in four major Latin American cities. *Revista Panamericana de Salud Pública*, 17(5-6), 394-409.

White, H., McConnell, E., Clipp, E., Branch, L., Sloane, R., Pieper, C. and Box, T. (2002). A randomised controlled trial of the psychosocial impact of providing internet training and access to older adults. *Aging & Mental Health*, 6(3), pp.213-221.

Wiles, J., Leibing, A., Guberman, N., Reeve, J. and Allen, R. (2011). The Meaning of "Aging in Place" to Older People. *The Gerontologist*, 52(3), 357-366.

World Health Organisation. (2018). *Universal health coverage*. [online] Available at: http://www.who.int/universal_health_coverage/en/ [Accessed 5 Apr. 2017].

World Health Organisation. (2018). *Universal coverage - three dimensions*. [online] Available at: http://www.who.int/health_financing/strategy/dimensions/en/ [Accessed 15 Jan. 2018].

Wolf, M., Gazmararian, J. and Baker, D. (2005). Health Literacy and Functional Health Status Among Older Adults. *Archives of Internal Medicine*, 165(17), 1946-1952.

Wyszewianski, L. (2002). Access to Care: Remembering Old Lessons. *Health Services Research,* 37(6), 1441–1443.

Zamora, H. and Clingerman, E. (2011). Health Literacy Among Older Adults. *Journal of Gerontological Nursing*, 37(10), 41-51.

Zhang, M. (2017). *A Geographical Analysis of Food Access in the Greater Hartford Area of Connecticut.* (Doctoral dissertation). University of Connecticut Graduate School.

Appendix: Interview scheme D-SCOPE phase 2 (in Dutch)

1. Welkomsttekst

Hartelijk dank om ons bij u thuis te ontvangen en voor uw medewerking aan het onderzoek. Het D-SCOPE team is een internationale, multidisciplinaire onderzoeksgroep die bestaat uit onderzoekers van de Vrije Universiteit Brussel, Katholieke Universiteit Leuven, Universiteit Antwerpen, Universiteit Maastricht en Hogeschool Gent. D-SCOPE heeft als doel kennis te vergaren over de zaken die maken dat ouderen kwaliteitsvol in de eigen thuisomgeving kunnen blijven wonen. Hierbij is het noodzakelijk om de visie van ouderen, mantelzorgers en huisartsen te kennen. Daarom bent u samen met 100 andere ouderen geselecteerd om deel te nemen aan dit onderzoek.

A. Methodiek individueel interview en scenario

Een individueel interview is een één-op-één gesprek tussen interviewer en geïnterviewde. De eerste vragen zijn gesloten vragen die ik u kort ga stellen. Vervolgens starten we met het interview. Ik ga u open vragen stellen en daar soms op doorvragen. Er bestaan geen goede of verkeerde antwoorden. Het interview duurt ongeveer 45 min. Mag ik u er op wijzen dat dit gesprek op computer wordt opgenomen voor de verdere verwerking. Ik zou graag willen beklemtonen dat de informatie die we krijgen tijdens dit interview strikt vertrouwelijk is en enkel in het kader van dit onderzoek zal worden gebruikt. U mag op ieder moment stoppen met het gesprek zonder dat u daarvoor een reden hoeft te geven. Dit alles is opgenomen in een informed consent. Ik heb een dubbeltje mee voor u. Zou u dit kunnen ondertekenen?

B. Opzet onderzoek

Met ons onderzoek willen we te weten komen wat nu de bepalende zaken zijn die maken dat ouderen kwaliteitsvol in de eigen thuisomgeving kunnen blijven wonen. Concreet is het interview uitgebouwd uit 2 grote delen. Het eerste deel zijn korte vragen waar u kan kiezen uit verschillende antwoordmogelijkheden. Nadien starten we met het interview. Wanneer er zaken niet duidelijk zijn voor u, aarzel niet om dit aan te geven. We vangen eerst aan met het schriftelijke deel.

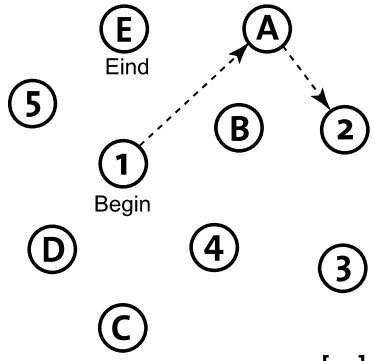
STAP 1: MOCA

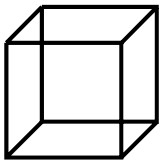
Nederlandse versie

MONTREAL COGNITIVE ASSESSMENT (MOCA)

Geboortedatum: **Naam:**
Jaren opleiding: **Datum:**
Geslacht:

VISUOSPATIEEL/EXECUTIEF — PUNTEN





Kopieer de kubus

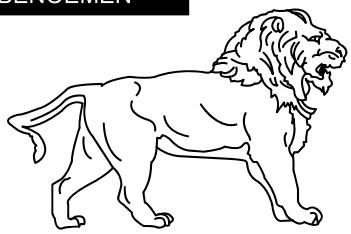
[ ] [ ]

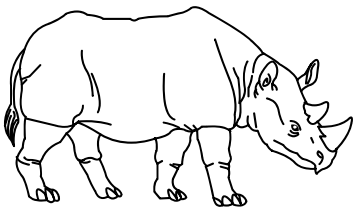
Teken een klok (tien over elf) (3 punten)

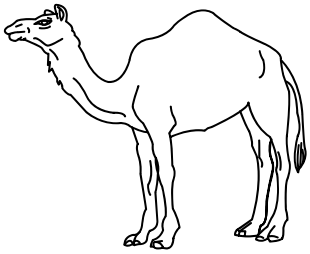
[ ] Omtrek [ ] Cijfers [ ] Wijzers

__/5

BENOEMEN







[ ] [ ] [ ]

__/3

GEHEUGEN — Lees de woorden op, proefpersoon moet ze nazeggen. Neem 2 maal af. Laat ze na 5 min. opnieuw opnoemen.

	GEZICHT	FLUWEEL	KERK	MADELIEF	ROOD
1e afname					
2e afname					

Geen punten

AANDACHT

Lees de rij cijfers op (1 cijfer/sec). Proefpersoon moet ze in dezelfde volgorde nazeggen **[ ] 2 1 8 5 4**

Proefpersoon moet ze in omgekeerde volgorde nazeggen **[ ] 7 4 2** __/2

Lees de rij letters op. De proefpersoon moet bij iedere letter A met zijn hand op de tafel tikken — Geen punten bij ≥ 2 ft

[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B __/1

Serieel 7 aftrekken, beginnend bij 100 **[ ] 93** **[ ] 86** **[ ] 79** **[ ] 72** **[ ] 65**

4 of 5 goed: **3 pt** 2 of 3 goed: **2 pt** 1 goed: **1 pt** 0 goed: **0 pt** __/3

TAAL

Zeg na: Ik weet alleen dat Jan vandaag geholpen zou worden. [ ]

De kat verstopte zich altijd onder de bank als er honden in de kamer waren. [ ] __/2

Fluency: Noem binnen één minuut zo veel mogelijk woorden die beginnen met de letter D **[ ]** (N ≥ 11 woorden) __/1

ABSTRACTIE — Overeenkomst tussen bijv. banaan en sinaasappel = fruit [ ] trein-fiets [ ] horloge-liniaal __/2

UITGESTELDE RECALL

	Woorden moeten herinnerd worden **zonder cue**	GEZICHT	FLUWEEL	KERK	MADELIEF	ROOD
		[ ]	**[ ]**	**[ ]**	**[ ]**	**[ ]**
Optioneel	Categoriecue					
	Meerkeuzecue					

Punten alleen voor recall zonder cue __/5

ORIËNTATIE — [ ]Datum [ ] Maand [ ] Jaar [ ] Dag [ ] Locatie [ ] Plaats __/6

www.mocatest.org

Normaal ≥ 26 / 30

TOTAAL __/30

Tel er 1 pt bij op indien ≤ 12 jr opleiding

STAP 2: CFAI

Heeft uw gezondheidstoestand u beperkt in de volgende activiteiten en zo ja, hoe lang al?

	1. Helemaal niet	2. 3 maanden of minder	3. Meer dan 3 maanden
1. Minder zware inspannende activiteiten (vb. boodschappen dragen).			
2. Een heuvel oplopen of enkele trappen lopen.			
3. Buigen, tillen of bukken.			
4. Een blokje stappen.			

Wanneer u de afgelopen weken in beschouwing neemt, in welke mate bent u het dan eens met de volgende uitspraken?

1 = Helemaal niet
2 = Niet meer dan gewoonlijk
3= Meer dan gewoonlijk
4= Opvallend meer dan gewoonlijk

	1	2	3	4
1. Ik voel me ongelukkig of depressief.				
2. Ik heb het gevoel dat ik m'n zelfvertrouwen verlies.				
3. Ik heb het gevoel dat ik de problemen niet aan kan.				
4. Ik heb het gevoel dat ik constant onder spanning sta.				
5. Ik heb het gevoel niks meer waard te zijn.				

In hoeverre bent u het eens met de volgende uitspraken?

1= Helemaal mee oneens
2= Mee oneens
3= Noch mee oneens / noch mee eens
4= Mee eens
5= Helemaal mee eens

	1	2	3	4	5
1. Ik heb moeite om te herinneren wat er pasgeleden is gebeurd.					
2. Ik heb moeite om mij gesprekken van een paar dagen geleden te herinneren.					
3. Ik ervaar moeilijkheden om nieuwe dingen te leren.					
4. Ik vind het moeilijk om te leren omgaan met nieuwe huishoudelijke apparaten.					
5. Ik ondervind moeilijkheden met het regelen van geldzaken, zoals pensioen, bankzaken …					
6. Ik heb moeite om het verhaal te kunnen volgen in een boek of op televisie.					

In hoeverre bent u het eens met de volgende uitspraken?

1= Helemaal mee oneens
2= Mee oneens
3= Noch mee oneens / noch mee eens
4= Mee eens
5= Helemaal mee eens

	1	2	3	4	5
1. Ik ervaar een leegte om mij heen.					
2. Ik mis mensen om mij heen.					
3. Ik voel mij vaak in de steek gelaten.					
4. Er zijn genoeg mensen op wie ik in geval van narigheid kan terugvallen.					
5. Ik ken veel mensen op wie ik volledig kan vertrouwen.					
6. Er zijn voldoende mensen met wie ik mij verbonden voel.					
7. Woning verkeert in slechte staat/is slecht onderhouden.					
8. Woning is weinig geriefelijk.					
9. Woning is moeilijk warm te stoken.					
10. Er is onvoldoende comfort in de woning.					
11. De wijk bevalt niet.					

Stel dat u voor een bepaalde tijd de activiteiten die u gewoonlijk doet in het huishouden niet zou kunnen uitvoeren, op wie kunt u dan een beroep doen?

1. Partner	
2. Zoon	
3. Schoondochter	
4. Dochter	
5. Schoonzoon	
6. Kleinkind	
7. Broer/zus (schoonbroer/schoonzus)	
8. Familie	
9. Buur	
10. Vriend	

Resultaat CFAI

CFAI Totaal	**NK**	**PK**	**K**
Fysiek	**NK**	**PK**	**K**
Psychologisch	**NK**	**PK**	**K**
Sociaal	**NK**	**PK**	**K**
Omgeving	**NK**	**PK**	**K**

NK: Niet Kwetsbaar

PK: Pre-Kwetsbaar

K: Kwetsbaar

STAP 2: Uitkomsten

Kwaliteit van leven

Hiermee wordt bedoeld wat u van uw leven vindt. Bijvoorbeeld of u tevreden met uw leven bent, of u plezier in uw leven hebt en of uw leven u voldoening geeft.

Op een schaal van 0 tot 10, hoe schat u uw kwaliteit van leven in op dit moment? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

Op een schaal van 0 tot 10, welk cijfer gaf u uw kwaliteit van leven 1 jaar geleden? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

Op een schaal van 0 tot 10, hoeveel zal u uw kwaliteit van leven binnen 1 jaar geven? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

Voldoende ondersteuning en zorg

Op een schaal van 0 tot 10, heeft u voldoende ondersteuning en zorg vandaag? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

Op een schaal van 0 tot 10, had u voldoende ondersteuning en zorg vandaag 1 jaar geleden? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

Op een schaal van 0 tot 10, zal u voldoende ondersteuning en zorg binnen 1 jaar hebben? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

Zingeving

Op een schaal van 0 tot 10, in hoeverre heeft u het gevoel dat uw leven zinvol (goesting, moeite waard, betekenisvol) is [dat u ergens naar uitkijkt of naar streeft] ? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

Op een schaal van 0 tot 10, in vergelijking met 1 jaar geleden, had u toen het gevoel dat uw leven zinvol was? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

Op een schaal van 0 tot 10, gaat uw leven zinvol zijn binnen 1 jaar? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

Regie

Op een schaal van 0 tot 10, hoeveel controle hebt u op de dingen die gebeuren in uw leven? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

Op een schaal van 0 tot 10, in vergelijking met 1 jaar geleden, hoeveel controle had u toen op de dingen die gebeurden in uw leven? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

Op een schaal van 0 tot 10, verwacht u binnen 1 jaar controle te hebben op de dingen die gebeuren in uw leven? ☐

Is dat cijfer volgens u goed of slecht?

NG	MM	G

NG: Niet Goed

MM: MiddelMatig

G: Goed

STAP 3: Kwalitatief interview

"Als mensen ouder worden wordt gezegd dat zij vaker kwetsbaarder worden."

- Hoe ervaart u kwetsbaarheid bij het ouder worden bij u zelf?
- Wat betekent kwetsbaar zijn voor u?
- Hebt u het gevoel dat u meer of minder kwetsbaar bent dan andere mensen van uw leeftijd?

Voelen ze zichzelf kwetsbaar? Over welke types kwetsbaarheid spreken ze specifiek?

"Heeft kwetsbaarheid volgens u een effect op een kwaliteitsvol en zinvol leven?"

- Hoe ziet u dat? Hoe ervaart u dat zelf?
- Wat maakt voor u dat uw leven kwaliteitsvol is, ook al bent u kwetsbaar?
- Wat maakt voor u dat uw leven zinvol (goesting, moeite waard, betekenisvol) is?
- Hoe kan u als kwetsbare oudere nog een kwaliteitsvol en zinvol leven hebben? Wat heb je daarvoor nodig?

Ook eens indirecte vragen gebruiken: wat maakt voor andere kwetsbare ouderen die ze kennen dat ze hun leven als kwaliteitsvol en zinvol ervaren?

"In welke mate heeft u het gevoel dat u zelf beslissingen kan nemen over wat er in uw leven gebeurt?"

- Hoe ziet u dat? Hoe ervaart u dat zelf?
- Hoe kan u zelf de regie houden over je leven? Wat hebt u daarvoor nodig?

Ook eens indirecte vragen gebruiken: is het ook voor andere kwetsbare ouderen die ze kennen belangrijk dat ze zelf de regie houden over hun leven?

"Wat moet een oudere doen om zijn of haar kwaliteit van leven te behouden als die kwetsbaar wordt?

- Hoe ervaart u dat zelf? Hoe ziet u dat bij u zelf?
- Welke factoren hebben daar volgens u een invloed op (*bij die oudere zelf*)?
    - Welke individuele kenmerken spelen een rol?
    - Welke rol speelt de mantelzorger hierin?
    - Welke rol speelt uw omgeving/buurt hierin?
    - Welke rol speelt de formele/professionele zorg hierin? (bv. poetshulp, kinesist, huisarts, verpleegkundige, gezinszorg …)

“Als u kijkt naar het voorbije jaar. Is uw leven veranderd?”

- Hoogtepunt:
    - Wat is uw meest positieve ervaring van het voorbije jaar?
    - Kan u dit in detail beschrijven? Wat gebeurde er, waar en wanneer, wie was er betrokken en wat dacht je en voelde je toen? Vertel ook waarom denkt u dat dit specifiek moment zo goed was.

      (Denk aan doorvragen als het gaat over individuele kenmerken, mantelzorger, rol van de buurt en formele zorg)

- Laagtepunt:
    - In tegenstelling tot het hoogtepunt heeft het voorbije jaar misschien ook een laagtepunt gekend? Kan u na gaan wat een laagtepunt was in het voorbij jaar?
    - Hoewel de gebeurtenis minder aangenaam is, stel ik het op prijs als je zoveel details als mogelijk zou kunnen vertellen. Wat gebeurde er? Waar en wanneer gebeurde het laagtepunt? Wie was er betrokken en wat dacht en voelde u? Beschrijf ook waarom u vindt dat dit moment zo slecht was?

      [Indien de respondent dit niet met je wil delen, zeg dan dat het niet HET laagtepunt van zijn verhaal moet zijn, maar dat een andere slechte ervaring ook ok is.]
      (denk aan doorvragen als het gaat over individuele kenmerken, mantelzorger, rol van de buurt en formele zorg)

- Verandering
    - Als u terugkijkt op het voorbije jaar, zijn er belangrijke veranderingen gebeurt in uw leven?
    - Kan u een aantal veranderingen beschrijven? Beschrijf weer voor deze gebeurtenis wat er gebeurde, waar en wanneer het gebeurde, wie er betrokken was en wat je dacht en voelde. Vertel ook kort wat je denkt dat deze gebeurtenis over u zegt als persoon of over uw leven.

      (Denk aan doorvragen als het gaat over individuele kenmerken, mantelzorger, rol van de buurt en formele zorg)

“Hoe kijkt u naar de toekomst voor uzelf? Als we één jaar verder zijn, zal uw leven veel veranderd zijn?”

- Hebt u specifieke verwachtingen naar de toekomst?
    - Welke dromen heeft u? Welke dromen wilt u realiseren?
        - Hoe gaat u die dromen realiseren?
    - Welke knelpunten verwacht u?
        - Welke acties onderneemt u nu al om aan die knelpunten iets te doen?

(*Denken ze dat ze nog een goede levenskwaliteit gaan hebben? Dat ze nog kwetsbaar gaan zijn?*)

Overgangen bestuderen: van huidig naar toekomst, op wat anticiperen ze zelf op wat kan komen. Protectieve factoren traceren tijdens transitiemomenten.

Extra vragen voor oudere respondenten van een organisatie

- Kunnen mensen langer thuis blijven door zorg24/Focus-Plus/AIPA?
    - Zo ja, door welke aspecten?
- Verhoogt het welbevinden van ouderen door zorg24/Focus-Plus/AIPA?
    - Zo ja, door welke aspecten?
- Wat als zorg24/Focus-Plus/AIPA er niet zou zijn? Zou uw leven er dan anders uitzien?

Tot slot: **Wie is uw huisarts?**

Mogen we die contacteren ? (cc gegevens)

Wie is uw mantelzorger?

Mogen we die contacteren ? (cc gegevens)

Waarom beschouwt u die als mantelzorger?

Omschrijving die wij hanteren van een mantelzorger meegeven bij twijfel. *"Persoon die vanuit een vanzelfsprekendheid op regelmatige basis de zorg opneemt voor een zorgbehoevende persoon in zijn directe omgeving, waarbij er naast de zorgrelatie ook sprake is van een verwantschapsrelatie (buur, vriend, familie) en waarbij de zorgverlener niet professioneel bezig is met de zorg" (Schoenmakers, Buntinx, De Lepeleire, Ylieff, & Fontaine, 2002).*

<u>Identificatiegegevens</u>

Wat is uw geboortedatum?

……..

Wat is uw geslacht?

1. Man	
2. Vrouw	

Wat is uw nationaliteit?

1. Belg	
2. Andere: ……..(vul in)	

Wat is uw land van herkomst?

1. België	
2. Ander: ……..(vul in)	

Wat is uw burgerlijke staat?

	Ja	
1. Gehuwd		Sinds…
2. Nooit gehuwd		

3. Gescheiden		Sinds…
4. Samenwonend		Sinds…
5. Weduwe(naar) / partner overleden		Sinds…
6. Kloosterling(e)		Sinds…

Met wie woont u samen?

	1. Ja	2. Neen
1. Partner		
2. Kind(eren)		
3. Kleinkind(eren)		
4. Ouder(s)		
5. Andere(n)		

Chapter 4 : Exploring the cost of 'ageing in place' : expenditures of community-dwelling older adults in Belgium

Abstract

This paper aims to give an overview of the different sources of income and the expenditures of community-dwelling older adults and to what extent they can make ends meet to explore the affordability of care and support at home. Despite research on the affordability of residential care, evidence on the cost of 'ageing in place' is still missing. 173 questionnaires were gathered within a non-random sample of community-dwelling older adults (60+). Both frequencies and bivariate tests (to explore whether there are certain risk groups with low incomes and high expenditures) were performed on the data. Results indicate the variety of income sources, the necessity of financial compensations to make ends meet and that especially older women and older tenants are at risk for facing financial difficulties. Also, this research indicates that 'ageing in place', especially for older adults with care needs, is not always affordable and can be a challenge within our ageing society.

Keywords: Ageing in place, income, expenditures, financial accessibility, older adults

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4.1. Introduction

In recent research, growing attention is paid to the financial situation of older adults (Randel et al., 2010; Schöllgen et al., 2010; Oris et al., 2017). An updated version of the Europe 2020 indicators concerning poverty and social exclusion pointed out that 17.4% of the population aged 65 and over in EU countries is facing the risk of poverty (Eurostat, 2017). Also, the income inequality among older adults is increasing: for example, in Belgium the median income for people older than 65 (€ 18021/year in 2016) is less than 80% of the median income for people younger than 65 (€ 23675/year in 2016) (Eurostat, 2017; Eurostat, 2018). Conversely, as people are ageing, they are generally confronted with rising costs and expenditures often facing multiple health-related conditions (Lubitz et al., 2003; Lehnert et al., 2011). Although 'ageing in place' is preferred by older adults and it is often being posited as more cost-effective than residential care by policymakers, limited research has been conducted on the effective cost of 'ageing in place' for older adults and whether this is financially feasible with rising care costs (Chapell et al., 2004; Grabowski, 2006; Means, 2007). A lot of attention in research has been spent to solely care expenditures of older adults facing specific medical conditions (e.g. diabetes, depression, gout, etc.) (Balkrishnan et al., 2003; Katon et al., 2003; Wu et al., 2008), but neglecting other life costs such as housing, living (nourishment, clothes, etc.), leisure, etc. This paper aims to explore the expenditures of community-dwelling older adults ageing in place, and to identify whether and when older people make ends meet.

Research concludes that the old-age at risk of poverty rate in Belgium is among the highest in Europe (15.4% for people above 65 compared to 14.6% for the same age group in the 28 EU-countries in 2016) (Haitz, 2015; Eurostat, 2018). According to the most recent European Union Statistics on Income and Living Conditions (2016), € 1115 is the minimum monthly income in Belgium that a person, living alone, needs in order to avoid the risk of poverty (Statbel, 2017). Older Belgians with limited working careers or insufficient financial resources can benefit from an arrangement in social security named the 'Income Guarantee for Older people (IGO)' (Berghman et al., 2016). However, data on IGO in 2017 learn that the maximum contribution for an older person living alone was € 1083.28 a month, which is beneath the above mentioned minimum income and remains insufficient to meet the minimum acceptable way of living in Belgium (Federale Pensioendienst, 2018).

Although, universal access to care and support has been prioritised by the World Health Organisation (WHO), European countries show large differences in their social security systems with different types of coverage (Pacolet et al., 2010; Evans et al., 2016; Marziale, 2016). As health insurance systems are very heterogeneous across countries, the proportion of out-of-pocket payments (e.g. non-refunded

expenses for inpatient care, outpatient care, prescribed drugs and day care) also vary widely (Holly et al., 2005; European Hospital and Healthcare Federation, 2015). In Belgium, the average out-of-pocket spending is 18% of the total health spending which is higher compared with other western European countries such as Germany (14%) and France (7%) (OECD Health Statistics, 2015). Research also indicates that the access to health and care services in Belgium is generally good, but there are important disparities in unmet care needs among income groups (mostly for financial reasons) (European Commission, 2017).

In recent years, Belgium and other European countries have been confronted with a movement of 'socialisation of care'; indicating that care has been brought into society (Degrave and Nyssens, 2010; Dury, 2018; Hassink et al., 2014). This goes together with a European wide movement of 'de-institutionalisation' in elderly care where older people are encouraged to age at home for as long as possible (Antonen and Karsio 2016; Kubalčíková and Havlíková 2016; Van Durme et al., 2015). Corresponding with the wish of most older people to age in place, several projects have been set up by Belgian governmental institutions to make this also possible for frail older adults (Wiles et al., 2012; De Almeida Mello et al., 2016; Smetcoren et al. ,2018). A great deal of research has been conducted concerning the costs of residential care both for older people and for society (Johri et al., 2003; Chapell et al., 2004; Kok et al., 2015). These studies point towards the high costs of nursing homes and the difficulties older adults experience to pay for this residential care. For instance, recent research indicates that the mean price per month for a stay nursing home in Flanders was €1665 in 2017, which is far above the average Belgian pension (about €1.225/month) (Socialistische Mutualiteiten, 2017; De Witte, 2018; Pacolet et al., 2018).

On the other side, research about the cost of living at home for older adults with care needs is still very limited. A recent survey of Elchardus (2016) pointed out that 24% of older respondents from low income categories experience difficulties in paying for homecare. Although there are several studies on the price of homecare, to our knowledge there is at present no existing study that takes into account all costs older adults with care needs have when living at home (Addae-Dapaeh and Wong, 2001; Davey, 2006; Costa-Font et al., 2009). A report about ageing in place in the European Union by Dr. Elizabeth Mestheneos (2011) is clearly mentioning the economic challenges for older adults that should be looked at broader than merely care expenditures: not only the increasing costs of care and support services, but also for example costs of energy-efficiency measures for older houses and housing adaptions should be taken into account.

Responding to the aforementioned research gaps, this paper aims to explore the extent to which ageing in place is affordable for older adults with care needs. Therefore, we used the following research questions:

1. What is the income of community-dwelling older adults with care needs?
2. What are the expenditures of community-dwelling older adults with care needs?
3. To what extent can community-dwelling older adults with care needs make ends meet and which profiles are at risk of having insufficient financial resources?

This paper/study explores all incomes and expenditures of older adults with care needs living at home in order to evaluate the affordability of care and support for community-dwelling older adults.

4.2. Methods

4.2.1. Data collection

The purpose of our research was to get a comprehensive view on all costs and expenditures that community-dwelling older adults with care needs are having. We conducted a quantitative research in which all sources of income and expenditures for the whole household during one month were monitored. A steering committee was established which consisted of professionals from an insurance company (as a provider of the Flemish Care Insurance), a large public healthcare organisation in Antwerp, an expertise center on elderly care in Brussels and occasionally representatives from the project partners, e.g. a social developmental organisation in Schaerbeek and a local service center for older people in Etterbeek were asked to join. This committee was responsible for all strategic choices concerning the research design and discussed the process of the research on a regular base.

The questionnaire for the respondents consisted of 16 pages containing four main parts: 1) socio-demographic characteristics, 2) data on care dependency, 3) the sources of income of the household and 4) the expenses of the household.

The purpose of the questionnaire was to monitor all actual costs during the period of one month. Before the beginning of the month, trained interviewers visited the older adults, gave information about the research and asked if they were willing to participate. People that agreed to participate in the research were asked to sign an informed consent. Finally, the interviewer went through the questionnaire together with the older adult and explained which sheets and bills they had to collect during this month. After one month, the interviewer visited the older participant a second time to fill in the questionnaire based on the collected sheets and bills. Clients of the insurance company that were willing to participate received the questionnaire by post with a clear description of the procedure to fill in, and if needed an explanation by phone. In 2014, the questionnaire and the research procedure were tested with four older adults and adapted according to the feedback/evaluation resulting from these tests. The data collection took place in 2015-2016.

The purpose is to give an insight in different income sources of older adults with care needs. Sources of income were defined broader than only pension incomes; all sources of income of the household were taken into account. For example, when there were children still living at home, their sources of income were added. Also, reimbursements from the health insurance fund for medical treatments were calculated as an income. This is because medical consultations were calculated as full expenditures in the research.

4.2.2. Respondents

To examine the care costs and expenditures of community-dwelling older adults, structured questionnaires were conducted with community-dwelling older adults with care needs. Older adults were defined in this research as 60 years or older (WHO, 2015). Our study population were community-dwelling older adults living in Flanders and Brussels Capital Region where a non-random sample was taken. The participants were selected in three ways:

1. an insurance company recruited participants within their members receiving a compensation from the Flemish Care Insurance (The Flemish Care Insurance is a monthly budget of €130 for care dependent Flemish citizens facing specific conditions. Every Flemish citizen starting from the age of 26 is asked to pay a contribution (obliged in Flanders, voluntary in Brussels) of €50 to finance this insurance) (N= 25)
2. within the 'Active Caring Community' project, inhabitants with care needs in the project regions (Antwerp, the Brabant district in Brussels and Etterbeek) were questioned by professionals (N=54). (The 'Active Caring Community' project was one of the six 'Care Innovation' living labs that were set up by the Flemish Government between 2013 and 2016 in order to search for innovative solutions to tackle the challenges in elderly care. These challenges include a sharply rising demand for care, personnel shortages and budgetary restrictions (Smetcoren et al., 2018))
3. third bachelor university students 'Adult Educational Sciences' gathered questionnaires of older adults within their close network of family and friends, people from which they objectively knew they faced care needs (N=94)

A total of 173 usable questionnaires were gathered.

4.2.3. Variables

As dependent variables, we used the different sources of income (subjective income, objective income within a household), expenditures (housing expenditures, living expenditures (nourishment, clothes, etc.), leisure expenditures, expenditures on medical material, medical care expenditures, welfare expenditures, expenditures on informal care) (see appendix 1), the financial shortage within the household and the wish to spend more on informal care and groceries.

As independent variables, we used socio-demographic characteristics in our analyses, such as gender, nationality (Belgian / other nationality) and age (60-69, 70-79, 80+). As for socio-economic characteristics, we measured: marital status (married / cohabitating, never married/ living alone, divorced, widowed), home ownership status (home owner, tenant private market, tenant social housing), number of members of the household (living alone, household of two people, household of more than two people). Concerning health related characteristics, we added three variables in our analyses: number of chronical conditions (0, 1, 2, >3), hospital admissions in the last six months (yes, no), health insurance status (normally insured, having a higher reimbursement status (=people in Belgium that are facing specific conditions (being widowed, unemployed, handicapped and having a low income) can benefit from a higher reimbursement of healthcare expenditures within the Belgian national healthcare and indemnity insurance)).

4.2.4. Data analyses

Data were analysed using SPSS, version 24.0, (IBM). We performed data cleaning to remove all mistakes in typing or coding. We used frequency tables to give an insight in how frequent a variable or category appeared by percentage, mean or median. Furthermore, we performed different bivariate tests in SPPS (chi square tests, Mann Whithney tests, Kruskall-Wallis tests, t-tests and ANOVA) to explore whether there are certain risk groups with low incomes and high expenditures which exceed their income sources (Baarda et al., 2012).

Within the cross-tables, we explored whether there are differences between groups of respondents, e.g. is there a difference between men and women concerning expenditures?

4.3. Results

4.3.1. Description of the study sample

About 81.5% of participants indicated they suffered from at least one chronical condition (based on a list of chronical conditions included in the questionnaire) and 32.7% of the participants had been hospitalised the last six months before the questionnaire was conducted.

Concerning socio-demographic characteristics, 48.3% of the participants were 80 years or older and 6.9% didn't have the Belgian nationality. More than 50% of the participants were divorced or widowed (17.9% were divorced and 37.6% were widowed). Almost 50% of the participants were tenants (not owning a house).

Table 6 gives an overview of the socio-demographic, socio-economic characteristics and health related characteristics.

Gender	%	95% Confidence Interval
Female	60.7	53.4-68.0
Male	39.3	32.0-46.6
Age		
60 – 69 years old	21.5	15.4-27.6
70 – 79 years old	30.2	23.3-37.1
> 80 years old	48.3	40.8-55.8
Nationality		
Belgian	93.1	89.3-96.9
Other	6.9	3.1-10.7
Marital status		
Married / cohabitating	37.6	30.4-44.8
Never married / living alone	6.9	3.1-10.7
Divorced	17.9	12.2-23.6
Widowed	37.6	30.4-44.8
Home ownership status		
Home owner	50.6	43.1-58.1
Tenant (private market)	18.6	12.8-24.4
Tenant (social housing)	27.3	20.6-34.0
Other (e.g. living with children)	3.5	0.8-6.2

Number of members of the household		
Alone	59.5	52.2-66.8
With 2	35.8	28.7-42.9
> 2	4.7	1.6-7.9
Number of chronical conditons		
0	18.5	12.7-24.3
1	34.7	27.6-41.8
2	23.1	16.8-29.4
> 3	23.7	17.4-30.0
Hospital admissions in the last 6 months		
Yes	32.7	25.7-39.7
No	67.3	60.3-74.3
Health insurance status		
Normally insured	65.5	58.4-72.6
Higher reimbursement status	34.5	27.4-41.6

4.3.2. Income sources: big diversity among older adults

The median income was € 1461.1, with a range between €130, an older adult only benefiting from the Flemish Care Insurance (this concerned an outlier, the second minimum income was €530) and a maximum of €7900, a household with high rental incomes.

About 88.8% of the participants benefited from a pension, 4% indicated that they still received an income out of a job and 16.8% (almost 1 out of 5) received sickness benefits. Almost 3 out of 10 participants received a compensation out of the Flemish Care Insurance, which means they were objectively categorised as 'frail' by a care professional (i.e. a score of 35 or more on the BEL-profile scale (which is an ADL-scale) or a score of 15 or more on the medical-social scale giving access to an 'allowance of assistance to older adults'). About 15% of the participants received reimbursements from a health insurance fund (up to €487 a month; mean €60.5 a month), which means they were having medical care costs in a short period before. Also 5.2% and 4.6% of older adults received financial contributions, respectively 'chronical illness benefits' (=benefit within the national health insurance for people facing severe chronical illness) or 'allowance of assistance to older adults' (=allowance for people older than 65 that have a low income and a certain level of dependency).

Table 7 presents an overview of the different sources of income within a household in one month.

Sources of income	Older adults that receive incomes in these category					
	%	Min €	Max €	Second max €	Mean €	Median €
Pension	88.8	340.0	3804.9	3400.9	1450.9	1344.2
Rental income, annuity, other regular incomes	8.7	130.0	6500.0	1655.0	1067.0	530.0
Income out of work	4.0	500.0	3000.0	1700.0	1424.0	1300.0
Unemployment benefits	0.6	1058.7	1058.7	0.0	1058.7	1058.7
Sickness benefits	16.8	19.1	2083.4	1439.4	359.5	379.7
Income from the social service of the municipality	2.3	5.0	850.0	775.5	557.6	687.7
Scholarships or child benefits	1.7	143.2	250.0	165.0	186.1	165.0
Reimbursements of the health insurance fund	15.0	17.0	487.0	212.0	99.1	60.5
Flemish Care Insurance and other informal care benefits	27.2	50.0	1200.0	700.0	171.7	130.0
Chronical illness benefits	5.2	37.5	278.0	180.0	116.9	108.0
Allowance for assistance to older adults	4.6	6.3	330.0	273.4	159.8	165.0
Other	5.8	14.5	643.0	460.0	237.2	210.0
Total income within the household	**100**	**130.0**	**7900.0**	**4300.0**	**1671.9**	**1461.1**

Table 8 presents the subjective income, 31.4% of the respondents declared to have financial difficulties at the end of the month, while only 18.6% of the respondents declared to have no financial difficulties.

Table 8. Subjective income

Subjective income	%	95% Confidence Interval
Has severe difficulties to make the ends meet	8.1	4.0-12.2
Has difficulties to make the ends meet	23.3	17.0-29.6
Making the ends meet is rather difficult	27.9	21.2-34.6
Can make the ends meet rather easily	22.1	15.9-28.3
Has no difficulties to make the ends meet	16.3	10.8-21.8
Has certainly no difficulties to make the ends meet	2.3	0.1-4.5

4.3.3. Expenditures: living at home with care needs is expensive

Housing appeared to be a substantial cost with a median of €450, as well as living expenditures (median €397.1). Welfare expenditures (i.e. family caregiving, household support (providing assistance with cooking, groceries, cleaning, some ADL and IADL tasks, keeping the older adult company) as well as meals on wheels, chores, cleaning aids, etc.) (median €141.7) and also expenditures on medical material (median €72.6) exceeded medical care expenses (median €69)

The participants in this study were asked to estimate their costs for informal care. Most of the informal caregivers had to make extra travel expenditures (median €40 in a month), expenditures for the washing of clothes and linen of the older adults (median €40 in a month), expenditures for professional help in the household (median €144 in a month) Some older adults had to reduce their professional activities which resulted in a loss of income (median loss of €225 in a month).

The median for all the expenditures within a household in one month was €1382.0.

Table 9 presents an overview of the expenditures within a household in one month.

Table 9. Overview of expenditures within a household in one month

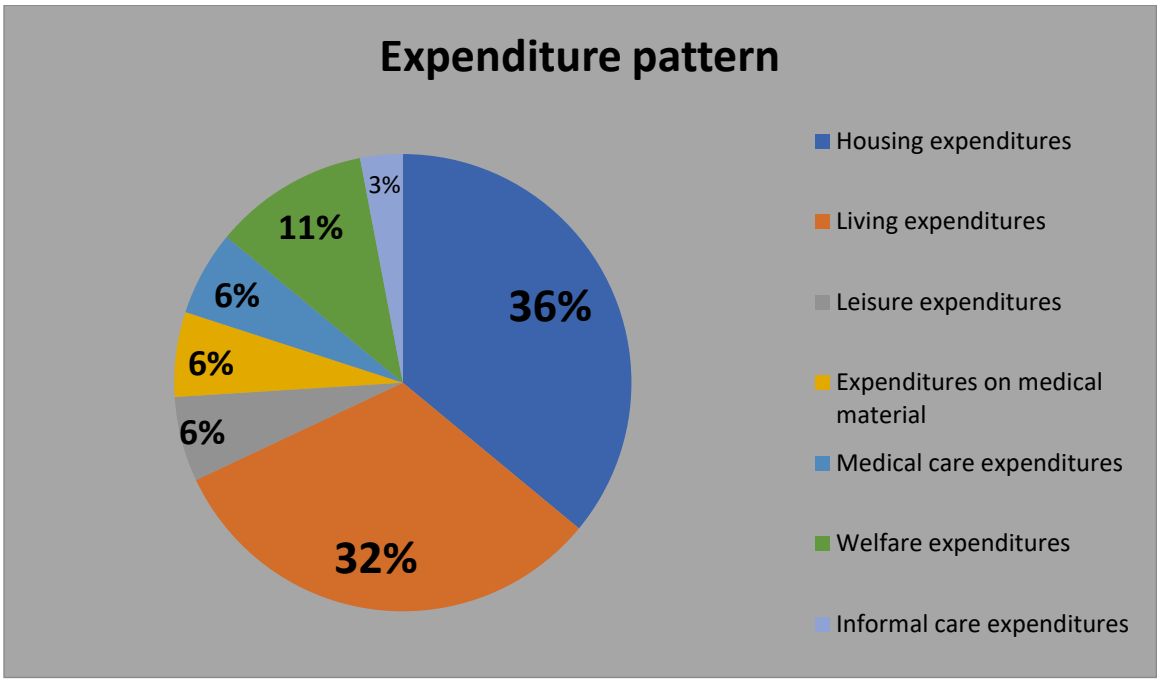
Sources of expenditures	Older adults with expenditures in these category					
	%	Min €	Max €	Second max €	Mean €	Median €
Housing expenditures	98.8	40.0	3801.2	3400.0	693.5	450.0
Living expenditures	99.4	88.0	1375.1	1019.9	455.1	397.1
Leisure expenditures	80.8	4.0	1170.0	814.8	130.4	70.0
Expenditures on medical material	87.2	1.7	800.0	600.0	104.9	72.6
Medical care expenditures	90.9	1.0	750.0	615.0	123.0	69.0
Welfare expenditures	90.9	6.0	1245.5	1172.2	215.1	141.7
Informal care expenditures	26.6	1.0	770.0	240.0	70.9	33.5
Total expenditures within the household	**100**	**328.0**	**5442.2**	**5735.1**	**1626.1**	**1382.0**

4.3.4. Care expenditures are more than medical care expenditures

The proportion of welfare expenditures (family caregiving, cleaning and household support, etc.) was high within the care and support expenditures of older adults. Welfare expenditures (11%) were after housing expenditures (36%) and living expenditures (32%) the largest expenses for the older adults.

Figure 4 presents an overview of the expenditure pattern of older adults within the sample.

Figure 4. Expenditure pattern of older adults



4.3.5. Risk profiles

Looking at the households on an individual level within the sample, the largest shortage to pay for all expenses in one month was €3651.7 followed by €2986. About 34.4% of the respondents did not have enough income to pay for all expenditures.

We explored whether there are significant differences concerning expenditures and shortages between groups of respondents (between men and women; between Belgian respondents and respondents from other nationalities; between respondents of 60-69 years old, 70-79 years old and > 80 years old, etc.) to identify risk groups.

Women experienced more difficulties to make the ends meet than men; respectively 44.4% and 30.9% of the respondents had a negative balance at the end of the month. The older the respondent, the more financial difficulties, although this effect was limited. Older adults living alone or that were never married faced the biggest risk to experience financial difficulties: Consequently, 57.1% had a negative balance at the end of the month.

In the field of housing, especially tenants of the private market experienced financial difficulties. But also, owners or couples in a social housing didn't have a lot of monetary reserves. About 44.8% of the older tenants on the private market didn't have enough resources, for 27.9% of the older tenants on

the social housing market this was also the case and 35.4% of the older home owners were in this situation.

Households with more members (>3) also seemed to be at risk for experiencing financial difficulties, 50.0% of older adults living in a household with more than two people experienced financial difficulties in comparison with 32.2% of older adults living alone.

Table 10 gives an overview of differences in expenditures by individual characteristics.

Table 10. Differences in expenditures by individual characteristics

	Mean expenditures within a household €	Median expenditures within a household €	Shortages within a household %
Gender			
Male	1579.4	1290.9	30.9$^{\alpha}$
Female	1759.3	1538.5	44.4$^{\alpha}$
Nationality			
Belgian	1699.3*	1462.0*	36.6
Other	1050.0*	992.4*	33.3
Age			
60 – 69 years old	1615.8	1337.1	33.3
70 – 79 years old	1631.1	1455.2	36.2
> 80 years old	1668.2	1381.8	36.8
Marital status			
Married / cohabitating	2142.7**	1802.4**	41.9
Never married / living alone	1273.4**	1337.1**	57.1
Divorced	1363.8**	1271.0**	31.0
Widowed	1342.9**	1180.5**	30.5
Home ownership status			
Home owner	1801.6*	1514.5*	35.4
Tenant (private market)	1612.4*	1333.0*	44.8
Tenant (social housing)	1284.7*	1163.0*	27.9

Health insurance status			
Normally insured	1727.1	1518.6*	34.3
Higher reimbursement status	1496.3	1183.3*	40.7
Number of chronical conditions			
0	1289.9$^{\alpha}$	1136.6*	28.6
1	1678.4$^{\alpha}$	1454.4*	36.4
2	1607.4$^{\alpha}$	1331.0*	35.1
> 3	1929.3$^{\alpha}$	1584.8*	43.2
Hospital admission in the last 6 months			
No	1563.4	1294.8*	35.5
Yes	1855.6	1565.4*	36.7
Number of members of the household			
Living alone	1335.1**	1192.2**	32.2
With 2	2038.5**	1757.0**	40.7
> 2	2502.1**	2305.6**	50.0

** level of significance < 0.01, there are highly significant differences between groups

* level of significance < 0.05, there are significant differences between groups

$^{\alpha}$ level of significance between 0.05 and 0.10, there is only a tendency of a significant difference

4.4. Discussion

This paper reports whether living at home with care needs is affordable for older adults. Within a sample of community-dwelling older adults with care needs we explored their household incomes, all their expenditures, to what extent they can make ends meet and which profiles are at risk of having insufficient financial resources.

In response to the first research question, the results show a large diversity in income sources among older adults with care needs. The monthly median income of older adults within our sample was €1461.1, which is beneath the monthly median income (€1557) of Belgian older adults (60 years or

older) in 2016 (Eurostat 2018). It means that the study sample was a bit more financially deprived than the Belgian average. Not only the amount of income varies widely, the total income of older adults is composed out of a large range of different sources (pensions, Flemish Care Insurance and other informal care benefits, sickness benefits, reimbursements of the healthcare fund, etc.). Excluding the pensions, different sorts of health-related benefits and compensations paid by the government or the health insurance fund are the most frequent source of income: compensations from Flemish Care Insurance and other informal care benefits, sickness benefits, reimbursements of the healthcare fund. This could be explained by the higher level of vulnerability among the study participants. In comparison with the average of Flemish older adults, this study reached a relatively high percentage of older adults with a migration background (7% in the study population vs. 1.7% in Flanders), contained a high number of divorced and widowed older participants (17.9% divorced and 37.6% widowed in the study population vs. 4.1% divorced and 33.5% widowed in Flanders) and had a high percentage of older adults suffering from multiple chronical conditions (46.8% vs. 42.7% high frail older adults in Flanders) (Dury et al. 2016; Fret et al. 2017). In addition, 34.5% of the people in our sample benefit from a 'higher reimbursement status', while this is 18% for the whole Belgian population (all ages) in 2016 (Goedemé et al., 2017). Research states that the knowledge and attribution of the different financial compensations and contributions given by the government and healthcare funds remains a challenge for people with a low-income status in Belgium (Hernanz et al., 2004; Eeman and Van Regenmortel, 2014). Moreover, the sixth Reform of the State of 2014 which transferred of a lot of competences within health- and social care from the Federal State to the Regional authorities has made the already complex Belgian financing system even more unclear both for professionals and for users (Dumont 2015; Koning Boudewijnstichting 2017). For example, concerning the 'higher reimbursement status' research indicates that in the last years 500.000 older adults meeting the criteria didn't benefit from it (Goedemé et al. 2017).

Concerning the second research question on expenditures, this study made an overview of all expenditures within a household: housing expenditures, living expenditures (e.g. nourishment, clothes), leisure expenditures, expenditures on medical material, medical care expenditures, welfare expenditures (e.g. family caregiving), and expenditures on informal care. Housing and living expenditures showed to be biggest expenditures followed by leisure expenditures, welfare expenditures, expenditures on medical material and medical care expenditures. It is generally demonstrated that residential care facilities for older adults are very expensive (on average €56.30/day in 2017) (Van den Bosch, 2016, Vlaams Agentschap Zorg & Gezondheid, 2018), but this study highlights that living at home with care needs also costs a lot of money. Although 50.6% of the participants were home owners, 98.8% were facing considerable housing expenditures (median €460). In an

international context, many researchers came to the conclusion that a majority of older adults are 'housing-asset rich, but income poor' and home-ownership is promoted as a method to maintain welfare (Bradbury 2010; Smetcoren 2016). Nevertheless, several authors are putting questions to the poverty-reducing strategy of home-ownership pointing at different unevitable costs (renovation, adaptation, real estate taxes) (Dewilde and Raeymaeckers, 2008; Doling and Ronald, 2009), definitely for older adults who often reside in older and unsuitable housing which can pose a substantial risk for their health, independence and wellbeing. (Smetcoren et al. 2016)

A second conclusion points out that welfare expenditures (e.g. domestic aid, meals on wheels, etc.) take a proportion in the expenditures of older adults, because in Belgium these are coordinated by the Regional authorities but not reimbursed by the national health insurance (in contrast with for example home nursing); they need to be paid for on an hourly basis or per prestation according to the income (Claessens et al., 2011; Van der Gucht, 2016; Woonzorgdecreet 13 maart 2009). Consequently, welfare services have another status than medical care services in Belgium and are regarded financially less accessible (Cès et al., 2016). In addition, although a big part of medical care interventions in Belgium is reimbursed, the cost of medical material is often not included in this reimbursement and has to be provided by the client itself which resulted in high expenditures on medical material (median €72.6) (Royal Decree nr. 78 of 10 November 1967). Also, the informal caregivers face different expenditures considering the respondents (travel expenditures, less income because of the reduction of working time, etc.). This is in line with recent research about the economic impact of informal caregiving that the average spending of an informal caregiver in a month is about €84.39 on direct costs related to his task (Desmedt et al., 2016).

Answering the third research question, almost one out of three participants (31.4%) declared to experience difficulties to make ends meet (to have financial difficulties to pay for all costs) at the end of the month. This is a large percentage compared to the percentage of Belgian older adults being at risk of poverty (17.4%) (Statbel, 2017). Financial compensations and contributions are often a necessary part of the regular income to make the ends meet. In Flanders, some compensations (f.e. the Flemish Care Insurance), although also designed to support and validate the informal caregiver, are paid directly to the person with care needs and used as a necessary supplementary income (Bronselaer et al., 2016). Also concerning the IGO, a recent modification in the Belgian law changed the conditions to benefit from it; only people that have been living in Belgium for at least ten years (including five consecutive years) can apply for it, which can exclude some older people with a migration background (Law of 22 January 2017).

Concerning risk profiles, women, older respondents and respondents living alone are more at risk of experiencing financial difficulties. This is in line with previous research on risk of poverty among older people (Berghman et al., 2016). Considering the housing state, tenants of the private market seem to face the biggest risk of not meeting the ends. For older adults with a limited income, the high rental prices on the private housing market can form a risk for financial problems and poverty because these prices are not related to income conditions. Heylen and Winters (2009) found out that 41.3% tenants of 65 and older consider their housing cost as a problem, while this is 27.4% within the total population.

4.4.1. Limitations and future research

Our findings should be considered in the light of the following limitations. The sample in this research is not representative to make conclusions about the financial capacity of all older adults in Flanders and Brussels. In the study design, we have used a non-random sample with specific focus on older adults with care needs or health problems. We wanted to give an insight in their costs and expenditures and point at certain risks concerning affordability. To get a bigger picture on the financial situation of all older adults, further research needs to be conducted within a broader sample.

Furthermore, the participants were asked to collect and register their costs for one month. Yet it would be interesting to collect and register costs during a longer period to make an evaluation of the incomes and expenditures of older adults during a year. After all, not every month is the same; some months more expenditures are needed or have unforeseen costs than other months. Longitudinal research would make it possible to investigate big costs (Verpoorten, 2015).

4.5. Conclusion and policy implications

Overall, we can conclude that ageing in place with care needs is expensive and includes some risks concerning affordability. Especially welfare expenditures seem to take a relatively big share in the budget of older adults. In this frame, it could be advised that Governments investigate the possibility of a 'maximal invoice' for social care (which already exists in hospital care). This has already been suggested by previous researchers (Eeman and Van Regenmortel, 2013; Elchardus, 2017; Lei et al., 2016). Considering the fact that in the frame of the sixth Reform of the State of 2014, the competences on elderly care from the Federal State are transferred to the Regional Governments and that this transfer is still ongoing, it would be a good momentum for all responsible governmental entities to make agreements about automatic entitlements for all financial compensations and contributions. For the 'higher reimbursement status', the automatic entitlement has already partly been introduced, but not for all categories of entitled persons (Goedemé et al., 2017). The Flemish Government has already

made a good start with the introduction of the 'Flemish Social Protection' providing a 'care budget' for older and dependent people, but it remains unclear which implications the future person-centered financing system in elderly care shall have on the financial situation of older adults with care needs (Conceptnota Vlaamse Sociale Bescherming 2016; Woolham et al., 2017). Some additional attention could be paid to older tenants on the private renting market being especially at risk of payment problems, especially after the recent elevation of the rent guarantee that has to be paid in Flanders from two to three months (Voorontwerp Vlaams Huurdecreet 2017).

References

Addae-Dapaah, K. and Wong, G. K. M. (2001). Housing and the elderly in Singapore–financial and quality of life implications of ageing in place. *Journal of Housing and the Built Environment*, *16*(2), 153-78.

Anttonen, A. and Karsio, O. (2016). Eldercare service redesign in Finland: deinstitutionalization of long-term care. *Journal of Social Service Research*, *42*(2), 151-66.

Balkrishnan, R., Rajagopalan, R., Camacho, F. T., Huston, S. A., Murray, F. T. and Anderson, R. T. (2003). Predictors of medication adherence and associated health care costs in an older population with type 2 diabetes mellitus: a longitudinal cohort study. *Clinical therapeutics*, *25*(11), 2958-971.

Baarda, B., Bakker, E., Van der Hulst, M., Fischer, T., Julsing, M. and van Vianen, R. (2012). *Basisboek methoden en technieken: kwantitatief praktijkgericht onderzoek op wetenschappelijke basis.* Groningen [etc.]: Noordhoff Uitgevers.

Belgisch Staatsblad. Wet tot wijziging van de wet van 22 maart 2001 tot instelling van een inkomensgarantie voor ouderen**.** http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=nl&la=N&table_name=wet&cn=2017012706. Accessed 8 April 2018.

Berghman, D.M., Donvil, N. and Peeters, E.H. (2016). Sociale bijstand als indicator van armoede bij ouderen. *Belgisch Tijdschrift voor Sociale Zekerheid 16*(2), 189-215.

Bradbury, B. (2010). Asset rich, but income poor: Australian housing wealth and retirement in an international context. http://library.bsl.org.au/jspui/bitstream/1/2180/1/Asset_rich_but_income_poor.pdf. Accessed 7 juni 2018.

Bronselaer, J., Vandezande, V., Vanden Boer, L. and Demeyer, B. (2016). Sporen naar duurzame mantelzorg. Hoe perspectief bieden aan mantelzorgers. Brussel: Departement Welzijn, Volksgezondheid en Gezin, 1-405.

Cès, S., Flusin, D., Schmitz, O., Lambert, A.S., Pauwen, N. and Macq, J. (2016). Mantelzorgers van thuiswonende ouderen in België: een cruciale en complexe rol. Brussel: Koning Boudewijnstichting, 1-146.

Chappell, N. L., Dlitt, B. H., Hollander, M. J., Miller, J. A. and McWilliam, C. (2004). Comparative costs of home care and residential care. *The Gerontologist*, *44*(3), 389-400.

Costa-Font, J., Elvira, D. and Mascarilla-Miró, O. (2009). 'Ageing in place'? Exploring elderly people's housing preferences in Spain. *Urban studies*, *46*(2), 295-316.

Conceptnota Vlaamse Sociale Bescherming (2016). Brussel: Vlaamse Gemeenschap, 1-26.

Claessens, E., Vertriest, S., Vandijck, D. and Petrovic, M. (2011). *Gezondheidseconomische evaluatie* van *mantelzorg bij (zwaar*) *zorgafhankelijke ouderen in de thuiszorg*. Gent: Universiteit Gent.

Davey, J. (2006). "Ageing in place": the views of older homeowners On maintenance, renovation and adaptation. *Social Policy Journal of New Zealand*, *27*, 128.

De Almeida Mello J., Declercq A., Cès S., Van Durme T., Van Audenhove C. and Macq J. (2016). Exploring Home Care Interventions for Frail Older People in Belgium: A Comparative Effectiveness Study. *Journal of the American Geriatrics Society, 64* (11), art.nr. 10.1111/jgs.14410, 2251-2256.

De Decker, P. and Dewilde, C. (2010). Home-ownership and asset-based welfare: the case of Belgium. *Journal of Housing and the Built Environment*, 25(2), 243-62.

Degavre, F. and Nyssens, M. (2010). Care as a social construct. The case of home care workers in contemporary Belgium.

Desmedt, M., Bergs, J., Vertriest, S., Hellings, J., Petrovic, M. and Vandijck, D. (2016). De economische waarde van mantelzorg en de financiële impact ervan op de ziekteverzekering, Hasselt: University Press.

Dewilde, C. and Raeymaeckers, P. (2008). The trade-off between home-ownership and pensions: individual and institutional determinants of old-age poverty. *Ageing & Society*, *28*(6), 805-30

De Witte, K. (2018). *De Grote pensioenroof. En het plan om ons pensioen terug te winnen*. Berchem: EPO, 1-296.

Doling, J. and Ronald, R. (2010). Home ownership and asset-based welfare. *Journal of housing and the built environment*, 25(2), 165-73.

Dumont, D. (2015). De sociale zekerheid en de zesde staatshervorming: voorgeschiedenis en algemene beschouwingen. *Belgisch Tijdschrift voor Sociale Zekerheid 15*(2), 175-228.

Dury, S., De Roeck, E., Duppen, D., Fret, B., Hoeyberghs, L., Lambotte, D., Van der Elst, M., van der Vorst, A., Schols, J., Kempen, G., Zijlstra, G.A.R., De Lepeleire, J., Schoenmakers, B., Kardol, T., De Witte, N., Verté, D., De Donder, L., De Deyn, P.P., Engelborghs, S., Smetcoren, A and Dierckx, E. (2016).

Identifying frailty risk profiles home of dwelling older people: focus on sociodemographic and socio-economic characteristics. *Aging & Mental Health*, 7: 1–9.

Dury, S. (2018). Dynamics in motivations and reasons to quit in a Care Bank: a qualitative study in Belgium. *European Journal of Ageing*, 1-10.

Eeman, L. and Van Regenmortel, T. (2013). Automatische rechtentoekenning en proactief handelen. Een verkenning op lokaal niveau met bijzondere aandacht voor mensen met een laag inkomen. VLAS-Studies 4, 1-45.

Elchardus, M. (2017). Thuiszorg. Onderzoek in opdracht van de socialistische mutualiteit. VUB: TOR, 1-34.

European Commission (2017). State of Healh in the EU Belgium. Country Health Profile 2017. https://ec.europa.eu/health/sites/health/files/state/docs/chp_be_english.pdf. Accessed 6 April 2018.

European Hospital and Healthcare Federation (2015). Out-of-pocket payments in healthcare systems in the European Union. http://www.hope.be/wp-content/uploads/2015/11/99_2015_HOPE-REPORT_Out-of-pocket-payments-in-healthcare-systems-in-the-European-Union.pdf. Accessed 7 June 2018.

Eurostat (2017). Income distribution statistics. http://ec.europa.eu/eurostat/statistics-explained/index.php/Income_distribution_statistics#Income_inequalities. Accessed 26 February 2018.

Eurostat (2018). At-risk-of-poverty rate of older people by detailed age group - EU-SILC survey. http://ec.europa.eu/eurostat/tgm/refreshTableAction.do?tab=table&plugin=1&pcode=tespn050&language=en. Accessed 7 June 2018.

Eurostat (2018). Mean and median income by age and sex - EU-SILC survey. http://appsso.eurostat.ec.europa.eu/nui/submitViewTableAction.do. Accessed 28 May 2018.

Evans, D., Hsu, J. and Boerma, T. (2013). Universal health coverage and universal access. *Bulletin of the World Health Organisation*, *91*(8), 546-546A.

Federale Pensioendienst (2018). De IGO. http://www.onprvp.fgov.be/NL/futur/IGO/amounts/paginas/default.aspx. Accessed 8 April 2018.

Fret, B., Lambotte, D., Van Regenmortel, S., Dury, S., De Witte, N., Dierckx, E., De Donder, L., & Verté, D. (2017). Socio-demographic, socio-economic and health need differences between types of care use in community-dwelling older adults. *International Journal of Care and Caring*, *1*(3): 351–66

Goedemé, T., Van Gestel, R., Janssens, J., Lefevere, E., Lemkens, R. and De Spiegeleer, T. (2017). De proactieve flux: een succesvolle manier om de opname van de verhoogde tegemoetkoming te verbeteren. *CM-Informatie*, (270), 19-25.

Grabowski, D. C. (2006). The cost-effectiveness of noninstitutional long-term care services: Review and synthesis of the most recent evidence. *Medical care research and review*, *63*(1), 3-28.

Haitz, N. (2015). Old-age Poverty in OECD Countries and the Issue of Gender Pension Gaps. *DICE Report*, *13*(2), 73.

Hassink, J., Hulsink, W. and Grin, J. (2014). Farming with care: the evolution of care farming in the Netherlands. *NJAS-Wageningen Journal of Life Sciences*, *68*, 1-11.

Heylen, K. and Winters, S. (2009). Betaalbaarheid van wonen in Vlaanderen: De budgetbenadering. Steunpunt Ruimte en Wonen: Heverlee.

Hernanz, V., Malherbet, F. and Pellizzari, M. (2004). *Take-up of welfare benefits in OECD countries: A review of the evidence*. Social, Employment and Migration Working Papers 17. Paris: OECD.

Holly A, Lamiraud K, Chevrou-Severac H. and Yalcin T. (2005). Out-of-pocket payments for health care expenditures. In: Börsch-Supan A, Brugiavini A, Jürges H *et al.* eds. *Health, Ageing and Retirement in Europe. First Results from the Survey of Health, Ageing and Retirement in Europe*. Mannheim: Mannheim Research Institute for the Economics of Aging (MEA), 126–132.

Johri, M., Beland, F. and Bergman, H. (2003). International experiments in integrated care for the elderly: a synthesis of the evidence. *International journal of geriatric psychiatry*, *18*(3), 222-235.

Katon, W. J., Lin, E., Russo, J. and Unützer, J. (2003). Increased medical costs of a population-based sample of depressed elderly patients. *Archives of general psychiatry*, *60*(9), 897-903.

Koning Boudewijnstichting (2017). Kwetsbare ouderen thuis ondersteunen. Lokale krachten bundelen. https://www.kbs-frb.be/nl/Activities/Publications/2017/20170305pp. Accessed 8 April 2018.

Kok, L., Berden, C. and Sadiraj, K. (2015). Costs and benefits of home care for the elderly versus residential care: a comparison using propensity scores. *The European journal of health economics*, *16*(2), 119-131.

Kubalčíková, K. and Havlíková, J. (2016). Current developments in social care services for older adults in the Czech Republic: Trends towards deinstitutionalization and marketization. *Journal of Social Service Research*, *42*(2), 180-198.

Lehnert, T., Heider, D., Leicht, H., Heinrich, S., Corrieri, S., Luppa, M., Riedel-Heller, S. and König, H. H. (2011). Health care utilization and costs of elderly persons with multiple chronic conditions. *Medical Care Research and Review*, *68*(4), 387-420.

Lei, P., Feng, Z. and Wu, Z. (2016). The availability and affordability of long-term care for disabled older people in China: the issues related to inequalities in social security benefits. *Archives of gerontology and geriatrics*, *67*, 21-27.

Lubitz, J., Cai, L., Kramarow, E. and Lentzner, H. (2003). Health, life expectancy, and health care spending among the elderly. *New England Journal of Medicine*, *349*(11), 1048-1055.

Marziale, M. (2016). Universal Access to Health and Universal Health Coverage: Nursing contributions. *Revista Latino-Americana de Enfermagem*, *24*(0), e2667.

Means, R. (2007). Safe as houses? Ageing in place and vulnerable older people in the UK. *Social Policy & Administration*, *41*(1), 65-85.

Mestheneos, E. (2011). Ageing in place in the European Union. *Global Ageing*, *7*(2), 17-24.

OECD (2015). Country Note: How does health spending in Belgium compare? https://www.oecd.org/belgium/Country-Note-BELGIUM-OECD-Health-Statistics-2015.pdf. Accessed 8 April 2018.

Oris, M., Gabriel, R., Ritschard, G. and Kliegel, M. (2017). Long Lives and Old Age Poverty: Social Stratification and Life-Course Institutionalization in Switzerland. *Research in Human Development*, *14*(1), 68-87.

Pacolet, J. , Bouten, R. , Lanoye, H. and Versieck, K. (2000). *Social Protection for Dependency in Old Age. A Study of the Fifteen EU Member States and Norway*. Aldershot: Ashgate

Pacolet, J., Luyten, J., Op de Beeck, L., De Wispelaere, F., De Coninck, A. and Kuppens, S. (2018). Noodzaak en modaliteiten van een duurzaam systeem van prijscontrole voor de residentiële ouderenvoorzieningen in Vlaanderen. HIVA en LIGB: Leuven.

Randel, J., German, T. and Ewing, D. (2000). *The Ageing and Development Report*. London: Routledge.

Royal Decree nr. 78 of 10 November 1967 considering the execution of care professions, Federal Government: Brussels.

Schöllgen, I., Huxhold, O. and Tesch-Römer, C. (2010). Socioeconomic status and health in the second half of life: findings from the German Ageing Survey. *European Journal of Ageing*, *7*(1), 17-28.

Smetcoren, A. . S., De Donder, L., Van Regenmortel, S., Dury, S., De Witte, N., Kardol, M. J. M., & Verte, D. (2015). Woonsituatie van ouderen in Vlaanderen: detecteren van kwetsbare groepen. In P. De Decker, B. Meeus, I. Pannecoucke, E. Schillebeeckx, J. Verstraete, & E. E. Volckaert (Eds.), *Woonnood in Vlaanderen: Feiten/Mythen/Voorstellen* (pp. 183-194). Antwerpen -Apeldoorn: Garant.

Smetcoren, A. . S., Dury, S., De Donder, L., De Witte, N., Van Regenmortel, S., Kardol, M. J. M., & Verte, D. (2014). Denken over later? Attitudes van ouderen ten opzichte van verschillende woonvormen in Vlaanderen. *Ruimte & Maatschappij*, *6*(12), 14-38.

Smetcoren, A. (2016). *I'm not leaving!? Critical perspectives on 'ageing in place'*. (Published doctoral dissertation Vrije Universiteit Brussel). Brussels: University Press.

Smetcoren, A., De Donder, L., Duppen, D., De Witte, N., Vanmechelen, O. and Verté, D. (2018). Towards an 'active caring community' in Brussels. In: T. Buffel, ed. *Age-friendly cities and communities: A global perspective*, 1st ed. Bristol: Policy Press at the University of Bristol, 97-118.

Socialistische Mutualiteiten (2017). Rusthuisbarometer. https://www.bondmoyson.be/SiteCollectionDocuments/Pers%20en%20studiedienst/300/Rusthuisbarometer_december2017.pdf. Accessed 8 April 2018.

Statbel (2017). Armoede-indicatoren in België in 2016 (EU-SILC). https://statbel.fgov.be/nl/themas/huishoudens/armoede-en-levensomstandigheden/armoederisico#news. Accessed 6 April 2018.

Van den Bosch, K. (2016). Measuring social protection for older people with long-term care needs in Belgium. A report on the completion of an OECD data collection questionnaire. https://www.plan.be/admin/uploaded/201609011418490.REP_LTCOECD062016_11305.pdf. Accessed 1 Juni 2018.

Van der Gucht, A. (2016). Wat betekent goede zorg in Vlaanderen anno 2016?. *Geron*, *18*(4), 12-16.

Van Durme, T., Schmitz, O., Cès, S., Anthierens, S., Maggi, P., Delye, S., Mello De Almeida, J., Declercq, A., Macq, J., Remmen, R. and Aujoulat, I. (2015). A comprehensive grid to evaluate case management's expected effectiveness for community-dwelling frail older people: results from a multiple, embedded case study. *BMC geriatrics*, *15*(1), 67.

Verpoorten, R. (2015). *The packaging puzzle: An investigation into the Income and Care Packages of the Belgian Elderly Population.* (Published doctoral dissertation Katholieke Universiteit Leuven). Leuven: KULeuven.

Vlaams Agentschap Zorg & Gezondheid (2018). Hoeveel bedraagt de gemiddelde dagprijs in uw woonzorgcentrum? Meting 2017. https://www.zorg-en-gezondheid.be/dagprijzen. Accessed 7 June 2018

Voorontwerp van decreet houdende bepalingen betreffende de huur van voor bewoning bestemde goederen of delen ervan 14 juli 2017. Vlaamse Gemeenschap: Brussel.

WHO (2015). *World report on ageing and health.* Geneva: WHO press.

Wiles, J. L., Leibing, A., Guberman, N., Reeve, J. and Allen, R. E. (2012) The meaning of "aging in place" to older people. *The gerontologist*, *52*(3), 357-366.

Woolham, J., Daly, G., Sparks, T., Ritters, K. and Steils, N. (2017). Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment. *Ageing & Society*, *37*(5), 961-984.

Woonzorgdecreet 13 maart 2009, Besluit van de Vlaamse Regering betreffende de programmatie, de erkenningsvoorwaarden en de subsidieregeling voor woonzorgvoorzieningen en verenigingen van gebruikers en mantelzorgers. Vlaamse Gemeenschap: Brussel.

Wu, E. Q., Patel, P. A., Yu, A. P., Mody, R. R., Cahill, K. E., Tang, J. and Krishnan, E. (2008). Disease-related and all-cause health care costs of elderly patients with gout. *Journal of Managed Care Pharmacy*, *14*(2), 164-175.

Appendix: questionnaire on expenditures

1. What were the housing expenditures within your household during the last month?

	Amount (fill in please)
1. Rent or mortgage payment	€ ……..
2. Stay in a residential care facility (e.g. nursing home, home for disabled people, etc.)	€ ……..
3. Utilities (e.g. water, electricity, heating, etc.)	€ ……..
4. Common costs in an appartment buiding	€ ……..

2. What were the living expenditures within your household during the last month?

	Amount (fill in please)
1. Shopping bills (e.g. Aldi, Carrefour, local grocery store, Lidl, etc.)	€ ……..
2. Telephone– Mobile phone	€ ……..
3. Television	€ ……..
4. Internet	€ ……..
5. Newspapers – journals	€ ……..
6. Garbage (e.g. trash bags, recycling center)	€ ……..
7. Own transport (e.g. fuel maintenance, garage, ...)	€ ……..
8. Public transport	€ ……..
9. Taxi	€ ……..
10. Adapted or social transport	€ ……..
11. Hairdresser	€ ……..
12. Buying or restoring clothes	€ ……..
13. Washing salon	€ ……..
14. Paying off debts	€ ……..

15. Alimony	**€ ……..**

3. What were the leisure expenditures <u>within your household</u> during the last month?

	Frequency in a month (fill in please)	**Amount (fill in please)**
1. Restaurants and bars		**€ ……..**
2. Meals in the local service center		**€ ……..**
3. Travelling and excursions		**€ ……..**
4. Activities local service center, sport activities		**€ ……..**
5. Watching sport or cultural events		**€ ……..**
6. Presents		**€ ……..**

4. What were the expenditures on medical material <u>within your household</u> during the last month?

	Frequency in a month (fill in please)	**Amount (fill in please)**
1. Medication		**€ ……**
2. Bandages, disinfection material, ointments, droplets, etc.		**€ ……**
3. Injection needles		**€ ……**
4. Incontinence material		**€ ……**
5. Sondage and stoma material		**€ ……**
6. Mats		**€ ……**
7. Dietetic nutrition on prescription		**€ ……**
8. Other : (fill in) ……		**€ ……**

5. What were the expenditures on professional care <u>within your household</u> during the last month?

	Frequency in a month (fill in please)	Amount (fill in please)
1. General Practitioner	**…….. visits**	**€ ……**
2. Specialist doctor (e.g. eye doctor, cardiologist)	**…….. visits**	**€ ……**
3. Home nursing	**…….. visits**	**€ ……**
4. Family caregiving	**…….. hours**	**€ ……**
5. Cleaning help	**…….. hours**	**€ ……**
6. Service vouchers	**…….. hours**	**€ ……**
7. Grocery service (=specific service to help with groceries)	**…… times**	**€ ……**
8. Chores service	**…….. hours**	**€ ……**
9. Meals on wheels	**…… meals**	**€ ……**
10. Physiotherapist	**…… times**	**€ ……**
11. Osteopath, acupuncturist	**…… times**	**€ ……**
12. Guarding help	**…….. hours**	**€ ……**
13. Day care / short care	**…….. days**	**€ ……**
14. Night care	**…….. nights**	**€ ……**
15. Pedicure or podiatrist	**…… times**	**€ ……**
16. Dietist	**…… times**	**€ ……**
17. Occupational therapist	**…… times**	**€ ……**
18. Speech therapist	**…… times**	**€ ……**
19. Psychologist	**…… times**	**€ ……**
20. Personal assistant	**…….. hours**	**€ ……**
21. Personal alarm or other home automation systems		**€ ……**

6. What were the expenditures on informal care <u>within your household</u> during the last month?

E.g.. Your grandson goes shopping with you and you give him a tip of €2

	How many hours a <u>week</u> do you receive help from…. (fill in please)	Amount (fill in please)
1. Partner		**€ ……..**
2. Children		**€ ……..**
3. Grandchildren		**€ ……..**
4. Other family members		**€ ……..**
5. Friends and acquaintances		**€ ……..**
6. Neighbours		**€ ……..**
7. Volunteers		**€ ……..**
8. Other: (fill in) ……..		**€ ……..**

7. Which other big costs <u>your household</u> faced <u>last year</u>?

	Amount (fill in please)
1. Medical aids (f.e. wheelchair, walking frame, hearing aids, etc.)	**€ ……..**
2. Bike	**€ ……..**
3. Car – moped – motor cycle	**€ ……..**
4. Subscription public transport	**€ ……..**
5. Washing machine – drying machine	**€ ……..**
6. Computer – laptop - tablet	**€ ……..**
7. Mobile phone	**€ ……..**
8. Hospital admission	**€ ……..**

9. Insurance (e.g. fire insurance, building insurance, hospitalization insurance, family insurance, etc.)	**€ ……..**
10. Renovation	**€ ……..**
11. Home adaptations	**€ ……..**
12. Travelling	**€ ……..**
13. Membership fees	**€ ……..**
14. Subscriptions journals	**€ ……..**
15. Study expenses	**€ ……..**
16. Other: (fill in) ……	**€ ……..**

Chapter 5 : Preventive home visits among frail community-dwelling older adults. The added value of follow-up telephone calls.

Abstract

People in need of care and support do not always find appropriate services. This paper aims to explore the added value of monthly telephonic follow-up after preventive home visits. We used both monitoring data and qualitative semi-structured interviews (with older adults, formal and informal caregivers). Results indicate that a majority of older adults (N=92) received a regular follow-up of four telephone calls. The social aspect and involvement were mentioned by all three groups as a positive aspect within the program. Although being time consuming, this paper brings to attention that follow-up telephone calls after preventive home have an added value.

Keywords: Frail older adults; preventive home visits; follow-up telephones; ageing in place

5.1. Background

Although frailty mainly has been approached as a physical issue in the past (Fried et al., 2001; Viana et al., 2013), in more recent years researchers pointed to the necessity to operationalise frailty as a multidimensional and dynamic concept that considers the complex interplay of physical, cognitive, psychological, social and environmental factors (Armstrong et al., 2010; Bergman et al., 2007; De Witte et al., 2013; Dury et al., 2018). Also, older adults themselves experience frailty as more than merely a physical issue (Grenier, 2007). Although frailty goes together with an increasing demand of care and support (Bolin et al., 2008; Colombo et al., 2003; Lambotte et al., 2018), people in need of care and support do not always find appropriate services and are often left undetected (Herr et al., 2013; Dury et al., 2018).

Recent research indicates that 3.8% of Belgian community-dwelling older adults that reported to be in need of care, did not receive any assistance (Fret et al., 2017), while others report problems concerning care accessibility (long waiting lists, lack of availability of providers, long traveling distance, etc.) (Fret et al., 2018, under review; Goins et al., 2005; Saurman, 2016). Moreover, research indicates that 'ageing in place', despite being a major policy goal, can contain difficulties concerning affordability due to high expenditures for necessary care and support services (Fret et al. 2018; Humphries et al. 2016). These conclusions are in line with research indicating that a considerable number of older adults is facing unmet care needs or care shortages (De Witte et al., 2010; Hoogendijk et al., 2013; Herr et al., 2013), especially for social care (Vlachantoni, 2017). Particulary the oldest groups among older adults, regular smokers, homebound older adults, older people with poor socio-economic conditions, depression or limitations in instrumental activities of daily living (IADL) seemed to be vulnerable (Herr et al., 2013). These unmet needs are associated with a lack of informal support and a lack of awareness or reluctance within the older adults to use care (Cassado et al., 2011).

Several reasons for this reluctance to use care or to delay care services can be identified (Goins et al., 2005; Thorpe et al., 2011; Suurmond et al., 2016). Often language and communication barriers are mentioned as well as physical and psychological (e.g. perception, trust) barriers (Fitzpatrick et al., 2004; Suurmond et al., 2016). Also, more negative ageing self-perceptions by older adults were associated with a higher likelihood of health care delay and perceived barriers to care (Sun and Smith, 2017). Moreover, there has been some research about care and support avoidance behavior among older adults stating that the reasons for 'not seeking care' highly vary from organisational issues to high costs, having no health insurance and time constraints (Howse et al., 2004; Taber et al., 2015; Leyva and Taber, 2017). Thorpe (2011) came to the conclusion that both healthcare organisations and

providers should target their interventions by tackling these aforementioned barriers, in order to improve access to services and to prevent care avoidance or delay.

In response to these barriers older adults face, several outreaching, preventive health and home visit programs for community-dwelling older adults have been developed in various settings (e.g. after hospitalisation, targeting older adults with disabilities, etc.) (Huss et al.,2008; Mayo-Wilson et al., 2014; Pröfener et al., 2016). Although being effective in reducing falls, there is lack of evidence that preventive home visits have a positive effect on reducing mortality, institutionalisation or hospital admissions within a general population of community-dwelling older adults (Bouman et al., 2008; Grant et al., 2014; Luck et al., 2013). Also, evidence of a reduction in health care costs within populations that received preventive home visits is lacking (Liimatta, 2016). In line with Lette et al. (2015), the question arises to which target group at what moment preventive initiatives in elderly care are valuable.

Another question that has been raised by scholars, concerns the follow-up of preventive home visits (Mayo-Wilson et al., 2014). Studies indicate a lack of consensus on how effective follow-up programs should be organised (Mayo-Wilson et al., 2014; Vass et al., 2004). In recent years, substantial research has been conducted on post-discharge follow-up (e.g. after hospital discharge) to provide tailored care and support at home in order to meet older adults' needs (Crocker et al., 2012; Clari et al., 2015; Hardman et al., 2016; Mishra et al., 2016, Lewis et al., 2017). These studies pointed out that a good follow up is essential to prevent hospital (re)admission. Especially the study of Lewis et al. (2017) concluded that during follow-up calls patients were not sufficiently aware of the different care and support services available in the community. Follow-up calls after discharge seemed to be a potentially cost-effective strategy to identify unmet needs and potentially provide comfort and timely referrals where needed (Clari et al., 2015; Lewis et al., 2017).

Although there has been a considerable amount of policy attention and funding for researchers and healthcare providers concerning prevention programs within community-dwelling older adults in order to evaluate interventions which may reduce or delay institutionalisation, there has been limited focus on follow-up initiatives after an intervention or a preventive home visit (Cutchin et al., 2009; Mayo-Wilson et al., 2014; Mello et al., 2012; Van Durme et al., 2015). This paper aims to explore the added value of monthly telephonic follow-up (for older adults, (in)formal caregivers and society) after preventive home visits within a detection and prevention program for frail community-dwelling older adults.

5.2. Methods/Design

5.2.1. Intervention design

The present research took place within the Detection, Support and Care for older people – Prevention and Empowerment (D-SCOPE) project. The D-SCOPE project is a four-year research project (2015-2018) that investigates strategies for proactive detection of (potentially) frail, community-dwelling older people, in order to guide them towards adequate support and/or care. One of the main aims of the D-SCOPE research was to evaluate the developed detection and prevention program for frail older people, from early detection, over intervention to follow-up. The program intended to develop a method to easily, accurately and timely detect and prevent a negative frailty-balance (the recognition of two faces of human ageing, including both the gains and the losses) in older adults and to improve the quality and efficacy of care and support, which ultimately would increase their life satisfaction, meaning in life and mastery.

The D-SCOPE detection and prevention program was evaluated by means of a Randomised Controlled Trial (RCT). The RCT was conducted in three municipalities in Flanders (Belgium): Knokke-Heist, Ghent and Tienen. Study participants (N = 869) were community-dwellings older adults aged 60 years and over. The RCT compared usual care with an intervention that included a second preventive home visit from a professional caregiver, tailored care and support when needed, and regular follow-up telephone calls. The full protocol is described in Lambotte et al. (2018). The tailored care and support depended on the availability within the municipality, and could be formal (i.e. home care) or informal (e.g. leisure activities of an association or community center). A professional employed at the social service from the municipality performed the follow-up calls.

5.2.2. Data collection method: monitoring data

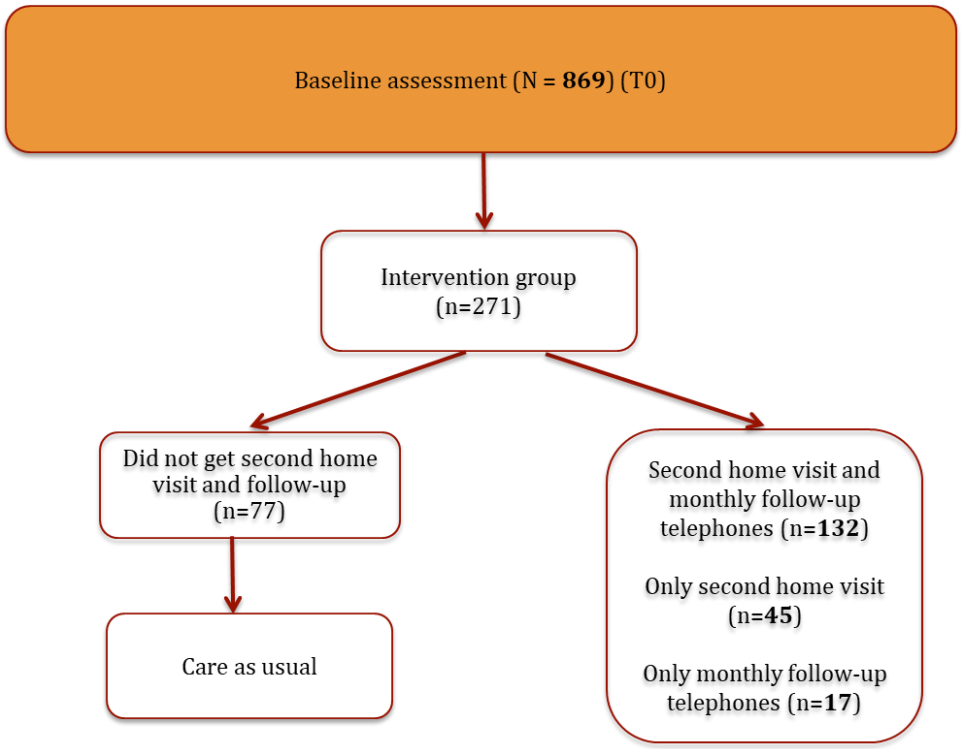
The present article investigates these telephonic long-term follow-ups and how these were experienced by the different stakeholders (i.e. older adults, informal caregivers and professionals) Therefore, we used both monitoring and qualitative data. We collected quantitative data considering the amount of follow-up telephones that were conducted. Each time the professional from the local social service called, she had to monitor following aspects: the questions asked to the professionals caregivers that contained which care or support questions the older adult faced after the second preventive home visit and whether an intervention was started and if so, which type of intervention. Also an overview of which steps that were undertaken in order to face the needs of the older adult was asked. The information asked to the older adults monitored which care or support the participant received, whether the person cancelled the assistance and if everything was going according to his/her

wishes. After conducting the follow-up telephones, the content of the phone calls was registered in designated fields in Qualtrics (an online survey tool for collecting and analysing data).

5.2.3. Sample characteristics

869 older adults were submitted to the baseline assessment (T0). 271 participants were assigned to the experimental group. Within these 271 older adults in the experimental group: 77 did not get a second preventive home visit from a professional employed at a local social service (as a consequence, they received care as usual); 132 adults received the second home visit and the monthly follow-up telephones; 45 only had the second home visit (without monthly follow-up telephones, due to time restrictions) and 17 older adults refused the second home visit from the professionals but were called monthly. In the present study, we report on the 132 older adults that received a second home visit and the monthly follow-up telephones and on the 17 older adults that only received the regular telephone follow-up. Figure 5 shows a schematic overview of the study sample.

Figure 5. Flow diagram of the study sample



5.2.4. Data collection method: qualitative data

To evaluate the experiences and value of the D-SCOPE program nine focus groups were organised: three with older participants in the experimental group (18 respondents), three with informal caregivers (from older participants in the experimental group) (15 respondents) and three with health and social care professionals from the municipality who performed the preventive home visits (11 respondents). The goal of the focus groups was to determine the participant's experiences, their opinions concerning the added value of the program and to identify components that support or inhibit the process of implementing the D-SCOPE program. The focus groups were held by a semi-structured interview schedule, developed following a literature review and input from the D-SCOPE steering group, consisting of 12 researchers from different research areas (i.e. adult educational sciences, gerontology, psychology, neurosciences, medicine) within different universities of the D-SCOPE consortium. The focus group interviews were conducted in March-April 2018.

Table 11. Respondents of the focus group interviews

Type of respondent	*Gender*	*Age (range; mean)*
18 older adults	7 men; 11 women	65-90 years old; mean: 76 years old
15 informal caregivers	8 men; 7 women	36-69 years old; mean: 58 years old
11 professional caregivers	3 men; 8 women	26-58 years old; mean: 44 years old

The semi-structured interview schedule of the focus groups consisted of the following major themes:

1. The experienced value of the D-SCOPE program (barriers within the project, added value of the program, recommendation to others, etc.)
2. Experiences with the first preventive home visit (questionnaire, length of the visit, etc.)
3. Experiences with the second preventive home visit conducted by a professional caregiver of the social service of the municipality
4. Experienced role as a professional caregiver
5. Experiences of the referral process (referral to and start of the professional help)
6. Experiences with the follow-up process (i.e. focus of this paper)

5.2.5. Ethical procedure

Prior to the baseline assessment and start of the intervention in the experimental group, a written consent was obtained from all participants. In case the participant was not able to sign the document,

a family member or another legal representative was allowed to sign it on their behalf, as stipulated by the Belgian civil code. In addition, before the focus groups, the participants were given an additional informed consent. Both times, respondents were informed about the voluntary nature of their involvement in the study, their right to refuse to answer, and the privacy of their responses. Also, respondents had the right not to participate in the study and to withdraw their consent at any time without negative consequences. Refusal to consent led to exclusion from the study. The study protocol was reviewed and approved by the medical ethics committee of the Vrije Universiteit Brussel, Brussels, Belgium (reference number: B.U.N. 143201630458).

5.2.6. Data analysis

Quantitative data were reported concerning the number of participants in the experimental group and the number of older adults that received the long-term monthly telephone follow-up. These data were analysed in SPSS, version 25.0 (IBM) using descriptive statistics. Furthermore, we reported on the content of the telephone calls, based on information that was inputted in Qualtrics by a professional of the social service of the municipality or the dispatcher. The content was analysed in an inductive way searching patterns in the data (bottom-up).

To evaluate experiences of the long-term follow-up process, the focus group interviews took place. All interviews were held in Dutch language and were digitally recorded (Audacity) with the participant's permission, and afterwards verbatim transcribed. Qualitative content analyses took place and codes were generated and analysed using the computer software program MAXQDA, which is a content analysis package with a good interpretive style (Elo, 2008; Kuş Saillard, 2011). All the categories and codings were developed in group by the researchers (author 1, 2 and 3) and refined until consensus was reached. Furthermore, the results of the analyses were discussed during a meeting with the steering committee.

5.3. Findings

5.3.1. Amount of follow-up telephones

Table 12 reports on the amount of follow-up telephones older adults received within the D-SCOPE program. Although it was the purpose within the study to perform a monthly telephonic follow-up, in practice that was not always evident for the professionals performing the calls, because they seemed to be very time consuming. Moreover, not all older adults found it necessary to receive a call every month. Nevertheless, a majority of 95 older adults received four follow-up telephone calls, which means they received a regular follow-up. All telephone calls were conducted between May 2017 and April 2018.

Table 12. Amount of follow-up telephones

Amount of telephones	*Frequency*	*Percentage (in %)*
1	*26*	*17.4*
2	*9*	*6*
3	*17*	*11.4*
4	*95*	*63.8*
5	*2*	*1.4*
Total	*149*	*100*

5.3.2. Content of the follow-up telephones: results of monitoring data within Qualtrics

According to the notes in Qualtrics, a majority of older adults asked for additional information during these follow-up calls concerning care and support services or contributions. These questions were not posed during the professional preventive home visits, but appeared later in the heads of the participants and were not actively voiced by them until asked to during the follow-up call. These questions not solely concerned the need for information, but also the need for assistance with applying for a service or contribution or referral to the right instance was often raised, as quoted underneath:

First phone call: "*The older adult asked about information on financial contributions. I sent him our brochures on elderly care."* Second phone call: "*I informed the older adult and explained to him which financial contributions there are".* During the third follow-up call: "*The older adult confirmed that he had received the brochures and that they were clear for him."* (monitoring data, Tienen)

Some older adults were asking (information) for specific services:

"*The older adult would like to know if her little trees could be pruned by the handy service of the municipality. I will arrange a social assistant to visit her to have a look at the situation."* (monitoring data, Tienen)

A certain number of questions raised by the older adults were about financial concerns/issues:

"An older man asked me if he could benefit from free trash bags. He said he knew other people that were benefiting from it which were having a higher income than him." (monitoring data, Ghent)

"*An older man asked me to check if he benefited from social telephone rates, because he didn't know if this was the case. I contacted his provider and at that moment, he didn't benefit from it. The provider will contact the man within a few days to investigate if he is eligible."* (monitoring data, Tienen)

"An older couple got a statement from the tax service and they have to pay back a lot of money. They wrongly received a big discount on registration taxes when they bought their house. We will follow their situation and propose to mediate with a payment plan." (monitoring data, Knokke-Heist)

In numerous cases the quotes of the professionals made clear that the actions/interventions following the phone calls led to a satisfying result:

The first phone call*: "I gave the contact details of the social service to the older adult. She would contact the social service in order to inform if she could benefit from support for the rental guarantee for her apartment."* During the second follow-up telephone: *"The woman mentioned that she was very happy, because she did receive support for the rental guarantee from the social service, which gave her the ability to move."* (monitoring data, Tienen)

"Thanks to our information the older woman contacted a cleaning service from which she is very satisfied." (monitoring data, Tienen)

Sometimes older adults reported to be fine and they didn't have any questions, however, when the professional called, they wanted to express their gratitude for the attention. They experienced the phone call as valuable and for this they were thankful to the professional. Some of them mentioned to look forward to the call in the future:

"*Everything is still all right with him and he appreciates being contacted from time to time to inform how he is doing."* (monitoring data, Tienen)

"The older man is expecting another phone call within a few weeks to be able to tell his story." (monitoring data, Knokke-Heist)

5.3.3. Experiences of the follow-up process: results from focus groups

The older participants considered the regular follow-up telephones as innovative and valuable within the project. Different respondents especially appreciated the personal attention and the personal contact. The dispatchers (professionals employed at the local social service) took the time to listen to their care needs and even remembered situations they talked about in a previous phone call. This kind of personal attention gave them a feeling of trustworthiness in the dispatcher and they felt more confident because the dispatcher would call them again in the future.

"I found these telephone calls very positive, that they did not forget about me and it wasn't just one phone call! It was really nice to know when the dispatcher told me they would call again the following month." (woman, Ghent, 72y)

"*During that period, the weather was really hot* (when the professional called her) *and they asked if we had enough water and drinks, etc. I found it very friendly to know that someone was thinking about me. I'm not used to that. It was really friendly. It made my day."* (woman, Knokke-Heist, 74y)

Older adults were very satisfied about the content of the telephone calls which allowed them to talk about all their worries but also fun things that had happened. Some participants were even surprised and emotionally affected that a professional took the time to call them. *"These telephone calls really moved me, I didn't expect them at all."* (man, Ghent, 90y).

They also repeatedly emphasised that the professional was interested in hearing their personal story and they had time to talk about important life events they experienced. *"When they called me, that were not just short conversations, I had the chance to tell my whole story."* (woman, Tienen, 73y)

Not only having someone who asks if help is needed, but also having a new contact to talk to was considered as an added value within these telephone calls. As explained by this older woman who especially appreciated the social aspect within the calls because she experienced a lack of social contact: *"I am not alone, but my husband doesn't say a lot and I don't have a lot of friends coming over."* (woman, Tienen, 73y)

One man mentioned that he would have preferred to receive an extra home visit instead of a telephone call, although he appreciated the fact that there was a follow-up: "*I found it regrettable that I had to talk to them through the telephone, I would have preferred if they came to my house. I like to see the face of who I am talking to."* (man, Tienen, 68y)

People also mentioned that since the D-SCOPE program has finished, they really regret that the telephone calls have ended.

The professional caregivers of the social service of the municipality were quite unanimous that these follow-up telephones were a big added value within the D-SCOPE project. During several follow-up conversations a care or support need was brought up by the older person (in cases where there was no original demand for care or support as voiced in the home-visit):

"Yes, I also think that this project has shown us that these regular telephones or a more regular follow-up, can be beneficial to our clients…. there are a lot of people refusing help or saying they don't need anything, but if you keep on calling and contacting them, suddenly they start talking about something serious that happened or that they are lonely". (professional, Knokke-Heist)

Although they were convinced of the importance of such follow up, the professionals also admitted that these conversations often were time consuming and thus costly. One of the participants noticed that it could be a good case if the telephonic follow-up would be continued by a volunteer in the future:

"It would be good to find a volunteer that could do these follow-up calls for a certain number of people. Sometimes, I called people every month that wanted to share their story and had them at the telephone for at least an hour. I could not end the conversation with the risk of missing important information." (professional, Ghent).

Given the frequency of such calls, some professional caregivers mentioned that in some cases a monthly follow-up was too frequent and not always necessary. They also mentioned that at some point it becomes the responsibility of the older adult to call when they are in need:

"I would prefer to say: is it ok that I call you back between three and six months from now to see if everything is all right. Or do you feel that is not necessary? And then I would give a flyer with my telephone number. I think it's a bit the responsibility of the people to contact us. But indeed, we as professionals can also call after a few months. It's just a matter of planning." (woman, Ghent, 60y).

The informal caregivers were very positive about these follow-up telephone calls, because they gave the ability to share their situation. In some cases, follow-up calls were not possible with the older adult (because of being too frail) so the dispatcher called to the informal caregiver. One informal caregiver especially mentioned the value of these phone calls because they gave the feeling not to be alone in this situation. She found it very regrettable the calls had stopped at the end of the program:

"I found it fantastic that they (cf. the dispatcher) *had so much time. I thought, there is really the time to talk for so long with me and that was really great. Maybe I'm a bit special, because my colleagues call me crazy we do all this* (cf. taking care of her mother-in-law). *But I can not talk about it with anyone, I can not talk about it with my husband, it's also his mother, he knows that. "That's typically mum" he*

just says, so there is really nobody I can talk to. I can not talk about it with my mother, because it has been my decision. So, it was very nice to be able to talk to someone." (woman, Gent, 47y)

Some informal caregivers did not receive these telephone follow-up calls and mentioned they would appreciate to be telephoned to be able to tell their story or to receive information about the older adult they care for. They mentioned it would make them feel more involved:

"If I call my mother, she says she hates telephone calls. So it's only: "everything is all right" and then bye. It's not that you want to ask something specific, but just if we know that someone already called I can ask my mother: "Have they called you?" and then she has to say "yes" (…). It's like the other person said, sometimes you also like to talk about the situation, what is going good or bad, to have a sort of soundboard." (man, Gent, 58y)

5.4. Discussion

This paper aimed to identify to which extent telephonic follow-up has an added value within the D-SCOPE detection and prevention program for frail community-dwelling older adults. Therefore, we used both monitoring data as well as qualitative semi-structured interviews.

Telephonic follow-up has already proven to be a(n) (cost-)effective strategy for providing comfort and timely referral for older adults after hospital discharge and to prevent hospital readmissions (Kirk, 2014; Lewis et al., 2017). Research also points out that telephonic follow-up improves the patients' satisfaction after hospital discharge (Braun, et al. 2009; Guss et al., 2013). The current research adds to the literature that follow-up telephone calls can be an effective and innovative strategy after preventive home-visits for frail community-dwelling older adults.

At first, we saw that a majority of older adults within the sample (N=95) received a regular follow-up of four telephone calls. As indicated by the professionals conducting the telephones, a monthly follow-up is very time consuming. Also, in some situations older adults as well indicated that being called monthly was too frequent. Nevertheless, the added value of a regular telephonic follow-up has already been proved by previous research. Courtney and colleagues (2006) for example stated that 4, 12 and 24 weeks follow-up telephone calls create a significantly better quality of life within older adults.

Concerning the content of the follow-up telephones different subjects were discussed with the older adults. A lot of information was asked by older adults about financial contributions, proving that despite efforts of proactive entitlement by the government and health insurance funds, literacy of social rights within older adults still cannot be taken for granted (Eeman and Van Regenmortel, 2014; Goedemé et al., 2017). Questions of older adults not solely concerned financial contributions but also

contact details or referral to health and homecare services. It is generally known that the Belgian institutional context is very complex. Moreover, the sixth Reform of the State of 2014, which transferred a lot of competences within health and homecare from the Federal State to the Regional authorities, has made the Belgian financing system even more unclear both for professionals as for users (Dumont, 2015; Koning Boudewijnstichting, 2017). In some cases, older adults did not have specific concerns or questions, but appreciated the attention and the occasion to tell their story. This links to research of Crocker and colleagues (2012) concluding that follow-up telephones have a positive impact on patient's engagement with their primary care providers. Older adults also appreciated the trustworthiness that they would be called again in the near future which gave them a certain peace of mind and the feeling of not being alone when serious life events would occur.

Exploring the experiences within the follow-up process, we can conclude that older adults, professionals and informal caregivers consider the follow-up telephones as being beneficial for the older persons. Older adults clearly appreciated the attention, the social contact and the interest in their story. This is a new aspect that that has not been emphasised in previous research on follow-up telephones, where more attention has been paid to the prevention of adverse outcome (hospitalisation, etc.) (Kirk, 2014; Lewis et al., 2017). Professional caregivers appreciated the repeated follow-up calls as an effective strategy to identify unmet needs that were not mentioned during preventive home visits. In the existing literature on preventive home visits, there is no consensus on their effectiveness of providing the ability of independent living to older adults (Mayo-Wilson et al., 2014). This results of this study might bring under attention that a repeated telephone follow-up program after preventive home visits might give better results on frail older adults' ability to age in place. Although it was not initially the purpose, some informal caregivers also received follow-up telephones. They clearly mentioned their appreciation stating that they felt supported and it gave them the ability to receive more information about the older adult they cared for, information that they could not receive from the older adult him/herself.

A pitfall of the follow-up telephones was that they were very time consuming and thus costly, certainly for professionals with an already heavy workload. Although being indicated as valuable, professionals within the study indicated that a monthly follow-up was not always feasible in practice.

5.5. Conclusion and policy implications

This paper brings to attention that follow-up telephone calls after preventive home have an added value for older adults, formal caregivers and informal caregivers. The social aspect and involvement were mentioned by these three groups as a positive aspect within the program. Professional caregivers underlined the potential of such telephones to identify unmet needs while informal caregivers

appreciated the ability on reducing informal caregivers' burden. Within our ageing society, where major attention is paid to 'socialisation of care' and the value of volunteers (Degrave and Nyssens, 2010; Dury, 2018), trained volunteers might have a role in telephone follow-up programs, certainly because no special equipment apart from a telephone is needed. As the follow-up telephones have been conducted during a limited period within a definite project, further research is desirable to identify their most effective way of organisation. Certainly, after the sixth Reform of the State (2014), the Belgian care and support sector is in full transition (as in other parts of Europe) with numerous new legislation being developed. This study provided a first exploratory research, further research could provide evidence on how follow-up programs can be implemented in practice and policy.

References

Armstrong, J.J., Stolee, P., Hirdes, J.P. and Poss, J.W. (2010). Examining three frailty conceptualizations in their ability to predict negative outcomes for home-care clients. *Age and ageing*, *39(*6), 755-58.

Bergman, H., Ferrucci, L., Guralnik, J., Hogan, D.B., Hummel, S., Karunananthan, S. and Wolfson, C. (2007). Frailty: an emerging research and clinical paradigm—issues and controversies. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *62*(7), 731-37.

Bolin, K., Lingren, B. and Lundborg, P. (2008). Informal and formal care among single-living elderly in Europe. *Health economics*, *17*(3), 393-409.

Bouman, A., van Rossum, E., Nelemans, P., Kempen, G. I. and Knipschild, P. (2008). Effects of intensive home visiting programs for older people with poor health status: a systematic review. *BMC health services research*, *8*(1), 74.

Braun, E., Baidusi, A., Alroy, G. and Azzam, Z.S. (2009). Telephone follow-up improves patients satisfaction following hospital discharge. *European journal of internal medicine*, *20*(2), 221-25.

Casado, B.L., van Vulpen, K.S. and Davis, S.L. (2011). Unmet needs for home and community-based services among frail older Americans and their caregivers. *Journal of Aging and Health*, *23*(3), 529-53.

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

Courtney, M., Edwards, H., Chang, A., Parker, A., Finlayson, K. and Hamilton, K. (2009). Fewer emergency readmissions and better quality of life for older adults at risk of hospital readmission: a randomized controlled trial to determine the effectiveness of a 24-week exercise and telephone follow-up program. *Journal of the American Geriatrics Society*, *57*(3), 395-402.

Crocker, J.B., Crocker, J.T. and Greenwald, J.L. (2012). Telephone follow-up as a primary care intervention for postdischarge outcomes improvement: a systematic review. *The American journal of medicine*, *125*(9), 915-21.

Cutchin, M.P., Coppola, S., Talley, V., Svihula, J., Catellier, D. and Shank, K.H. (2009). Feasibility and effects of preventive home visits for at-risk older people: design of a randomized controlled trial. *BMC geriatrics*, *9*(1), 54.

Degavre, F. and Nyssens, M. (2010). Care as a Social Construct: The Case of Home Care Workers in Contemporary Belgium', in T. Addabbo, M.P. Arrizabalaga, C. Borderías and A. Owens (eds.). *Gender Inequalities, Households and the Production of Well-Being in Modern Europe,* London: Routledge. pp. 145-62.

De Witte, N., Buffel, T., De Donder, L,. Dury, S. and Verté, D. (2010). Care shortages in later life: the role of individual and contextual variables in Flanders, Belgium. *International Journal of Social Sciences and Humanity Studies, 2*(1), 111-18.

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

De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Verte, D. and Schols, J. (2013). Validation of the comprehensive frailty assessment instrument against the Tilburg frailty indicator. *European Geriatric Medicine, 4*(4), 248–54.

Dumont, D. (2015) 'De sociale zekerheid en de zesde staatshervorming: voorgeschiedenis en algemene beschouwingen', *Belgisch Tijdschrift voor Sociale Zekerheid, 15*(2), 175-228.

Dury, S. (2018) 'Dynamics in motivations and reasons to quit in a Care Bank: a qualitative study in Belgium', *European Journal of Ageing*, 1-10.

Dury, S., Dierckx, E., van der Vorst, A., Van der Elst, M., Fret, B., Duppen, D., Hoeyberghs, L., De Roeck, E., Lambotte, D.F., Smetcoren, A-S., Schols, J.M.F.A., K, Kempen, G.I.J.M., Zijlstra, G.A.R., De Lepeleire, J., Schoenmakers, B., Verte, D., De Witte, N., Kardol, M.J.M, De Deyn, P.P., Engelborghs, S. and De Donder, L. (2018). Detecting frail, older adults and identifying their strengths: results of a mixed-methods study, *BMC Public Health*, *18*(1), 191.

Elo, S. and Kyngäs, H. (2008). The qualitative content analysis process. *Journal of advanced nursing*, *62*(1), 107-15.

Eeman, L. and Van Regenmortel, T. (2013). Automatische rechtentoekenning en proactief handelen. Een verkenning op lokaal niveau met bijzondere aandacht voor mensen met een laag inkomen. *VLAS-Studies 4,* 1-45

Fitzpatrick, A.L., Powe, N.R., Cooper, L.S., Ives, D.G. and Robbins, J.A. (2004). Barriers to health care access among the elderly and who perceives them, *American journal of public health*, 94(10), 1788-94.

Fret, B., Lambotte, D., Van Regenmortel, S., Dury, S., De Witte, N., Dierckx, E., De Donder, L., Verté, D. and D-SCOPE Consortium. (2017). Socio-demographic, socio-economic and health need differences between types of care use in community-dwelling older adults. *International Journal of Care and Caring*, *1*(3), 351–66

Fret, B., De Donder, L., Lambotte, D., Dury, S., Van der Elst, M, De Witte, N., Switsers, L., Hoens, S., Van Regenmortel, S., Verté, D. and D-SCOPE Consortium (2018). Access to care of frail community-dwelling older adults in Belgium: a qualitative study. *Primary Healthcare Research & Development*

Fret, B., Mondelaers, B., De Donder, L., Switsers, L., Smetcoren, A-S., Verté, D. and D-SCOPE Consortium (2018). Exploring the cost of 'ageing in place': expenditures of community-dwelling older adults in Belgium. *Ageing International*. https://doi.org/10.1007/s12126-018-9341-y.

Fried, L.P., Tangen, C.M., Walston J., Newman, A.B. Hirsch, C., Gottdiener, J., Seeman, T., Tracy, R., Kop, W.J. and McBurnie, M.A. (2001). Frailty in older adults. Evidence for a Phenotype. *The Journals of Gerontology: Series A, 56*(3), 146-56.

Goins, R.T., Williams, K.A., Carter, M.W., Spencer, S.M. and Solovieva, T. (2005). Perceived barriers to health care access among rural older adults: a qualitative study. *The Journal of Rural Health*, *21*(3), 206-13.

Goedemé, T., Van Gestel, R., Janssens, J., Lefevere, E., Lemkens, R. and De Spiegeleer, T. (2017). De proactieve flux: een succesvolle manier om de opname van de verhoogde tegemoetkoming te verbeteren. *CM-Informatie*, *270*, 19-25.

Grenier, A. (2007). Constructions of frailty in the English language, care practice and the lived experience. *Ageing & Society*, *27*(3), 425-45.

Grant, S., Parsons, A., Burton, J., Montgomery, P., Underhill, K. and Mayo-Wilson, E. (2014). Home visits for prevention of impairment and death in older adults: a systematic review. *Campbell Systematic Reviews, 10*(3), 1-13.

Guss, D.A., Leland, H. and Castillo, E.M. (2013). The impact of post-discharge patient call back on patient satisfaction in two academic emergency departments. *The Journal of emergency medicine*, *44*(1), 236-41.

Hardman, B. and Newcomb, P. (2016). Barriers to primary care hospital follow-up among older adults in rural or semi-rural communities, *Applied Nursing Research*, *29,* 222-28.

Herr, M., Arvieu, J.J., Aegerter, P., Robine, J.M. and Ankri, J. (2013). Unmet health care needs of older people: prevalence and predictors in a French cross-sectional survey, *The European Journal of Public Health*, 24(5), 808-13.

Hoogendijk, E.O., Muntinga, M.E., van Leeuwen, K.M., van der Horst, H.E., Deeg, D.J.H., Frijters, D.H.M., Hermsen L.A., Jansen, A.P., Nijpels, G. and van Hout, H.P.J. (2013). Self-perceived met and unmet care needs of frail older adults in primary care. *Archives of Gerontology and Geriatrics*, *58*(1), 37-42.

Howse, K., Ebrahim, S. and Gooberman-Hill, R. (2004). Help-avoidance: why older people do not always seek help. *Reviews in Clinical Gerontology*, *14*(1), 63-70.

Humphries, R., Thorlby, R., Holder, H., Hall, P. and Charles, A. (2016). Social care for older people. *London: The King's Fund and Nuffield Trust*.

Huss, A., Stuck, A.E., Rubenstein, L.Z., Egger, M. and Clough-Gorr, K.M. (2008). Multidimensional preventive home visit programs for community-dwelling older adults: a systematic review and meta-analysis of randomized controlled trials. *The Journals of Gerontology, Series A: Biological Sciences and Medical Sciences*, *63*(3), 298-307.

Kirk, C. (2014). Routine telephone follow-up of older people after hospital admissions, *Current Ageing Science*, *7*(2), 143-54.

Koning Boudewijnstichting (2017) *Kwetsbare ouderen thuis ondersteunen. Lokale krachten bundelen*, https://www.kbs-frb.be/nl/Activities/Publications/2017/20170305pp.

Kuş Saillard, E. (2011). Systematic Versus Interpretive Analysis with Two CAQDAS Packages: NVivo and MAXQDA. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 12*(1), 21.

Lambotte, D.F., De Donder, L., Van Regenmortel, S., Fret, B., Dury, S., Smetcoren, A-S., Dierckx, E., De Witte, N., Verte, D., Kardol, M.J.M. and D-SCOPE Consortium (2018) 'Frailty differences in older adults' use of informal and formal care', *Archives of Gerontology and Geriatrics*, 79: 69-77.

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

Lette, M., Baan, C.A., van den Berg, M. and de Bruin, S.R. (2015). Initiatives on early detection and intervention to proactively identify health and social problems in older people: experiences from the Netherlands. *BMC geriatrics*, *15*(1), 143.

Leyva, B., Taber, J.M. and Trivedi, A.N. (2017). Medical Care Avoidance Among Older Adults. *Journal of Applied Gerontology.* DOI: https://doi.org/10.1177/0733464817747415.

Lewis, E., Samperi, S. and Boyd-Skinner, C. (2017). Telephone follow-up calls for older patients after hospital discharge. *Age and ageing*, *46*(4), 544-46.

Liimatta, H., Lampela, P., Laitinen-Parkkonen, P., Pitkala, K.H. (2016). Effects of preventive home visits on older people's use and costs of health care services: A systematic review. *European Geriatric Medicine*, *7*(6), 571-80.

Luck, T., Motzek, T., Luppa, M., Matschinger, H., Fleischer, S., Sesselmann, Y., Rolling, G., Beutner, K., König, H-H., Behrens, J. and Riedel-Heller, S.G. (2013). Effectiveness of preventive home visits in reducing the risk of falls in old age: a randomized controlled trial. *Clinical Interventions in Aging*, 8, 697-702.

Mayo-Wilson, E., Grant, S., Burton, J., Parsons, A., Underhill, K. and Montgomery, P. (2014). Preventive home visits for mortality, morbidity, and institutionalization in older adults: a systematic review and meta-analysis. *PloS one, 9*(3). DOI: https://doi.org/10.1371/journal.pone.0089257.

Mello, J.D.A.., Van Durme, T., Macq, J. and Declercq, A. (2012). Interventions to delay institutionalization of frail older persons: design of a longitudinal study in the home care setting. *BMC Public Health*, *12*(1), 615.

Mishra, A.K., Aaron, S., Abhilash, K., Iyadurai, R., Shaikh, A., Lazarus, E., Alexander, V., George A.A., Vishali, P. and Sudarsanam, T.D. (2016). Simple telephone call a feasible, useful and acceptable method of following up patients with cerebrovascular accidents: Prospective Cohort study in South India. *International journal of stroke: official journal of the International Stroke Society*, *11*(8), 87-88.

Pröfener, F., Anders, J., Dapp, U., Minder, C.E. and Golgert, S. (2016). Acceptance of preventive home visits among frail elderly persons: Participants an non-participants in a Follow-up after 2 and 4 years within the LUCAS longitudinal study. *Zeitschrift fur Gerontologie und Geriatrie*, *49*(7), 596-605.

Saurman, E. (2016) Improving access: modifying Penchansky and Thomas's Theory of Access. *Journal of Health Services Research & Policy*, *21*(1), 36-39.

Sun, J.K. and Smith, J. (2017). Self-perceptions of aging and perceived barriers to care: Reasons for health care delay. *The Gerontologist*, *57(suppl_2),* 216-26.

Suurmond, J., Rosenmöller, D.L., el Mesbahi, H., Lamkaddem, M. and Essink-Bot, M.L. (2016). Barriers in access to home care services among ethnic minority and Dutch elderly – A qualitative study. *International Journal of Nursing Studies*, *54*, 23-35.

Taber, J.M., Leyva, B. and Persoskie, A. (2015). Why do people avoid medical care? A qualitative study using national data. *Journal of General Internal Medicine*, *30*(3), 290-97.

Thorpe, J.M., Thorpe, C.T., Kennelty, K.A. and Pandhi, N. (2011). Patterns of perceived barriers to medical care in older adults: a latent class analysis. *BMC Health Services Research*, 11: 181.

Van Durme, T., Schmitz, O., Cès, S., Anthierens, S., Maggi, P., Delye, S., De Almeida Mello J., Declercq, A., Macq, J., Remmen, R. and Aujoulat, I. (2015). A comprehensive grid to evaluate case management's expected effectiveness for community-dwelling frail older people: results from a multiple, embedded case study, *BMC Geriatrics*, *15*(1), 67.

Vass, M., Avlund, K., Kvist, K., Hendriksen, C., Andersen, C.K. and Keiding, N. (2004). Structured home visits to older people. Are they only of benefit for women? A randomised controlled trial. *Scandinavian Journal of Primary Health Care*, *22*(2), 106-11.

Viana, J.U., Silva, S.L., Torres, J.L., Dias, J., Pereira, L.S., Dias, R.C. (2013). Influence of sarcopenia and functionality indicators on the frailty profile of community-dwelling elderly subjects: a cross-sectional study. *Brazilian Journal of Physical Therapy*, *17*(4), 373-81.

Vlachantoni, A. (2017). Unmet need for social care among older people. *Ageing & Society*, 1-28.

Chapter 6 : General discussion

6.1. Reflection on the empirical results

The present doctoral dissertation aimed to explore which are the conditions to organise and provide access to high-quality care and support for (frail) community-dwelling older adults.

The following section provides an overview of the main study results accommodated within the four main research questions as they have been formulated in the introduction.

6.1.1. Research question 1

Which socio-demographic and socio-economic characteristics within community-dwelling adults can be associated with different types of care use?

With the first research question, we aimed to explore whether socio-demographic and socio-economic characteristics within community-dwelling adults can be associated with different types of care use.

In term of 'different types of care use', eight classes of formal and informal care were identified by using data from the Belgian Ageing Studies (De Donder et al., 2014) and by performing Latent Class Analysis **(study 1).** The first three classes of care use were characterised by older adults who were more likely to receive care that was dominated by informal caregivers. Class 1 consisted of older care recipients who were more likely to receive care only from nuclear family caregivers, that is, care from their spouse and/or children. Class 2 identified care recipients who were more likely to receive care from both nuclear and extended family caregivers, that is, care from their spouse, children, grandchildren and/or other relatives. Class 3 comprised older people who were more likely to receive care from all different types of informal caregivers, that is, nuclear and extended family caregivers, friends and acquaintances, and neighbours. Second, there were three classes of care use characterised by older adults who were more likely to receive care from both informal caregivers and formal care providers. Class 4 identified older adults who were more likely to receive care from all informal caregivers in combination with care from their general practitioner. Older care recipients in class 5 were more likely to receive care from all informal caregivers in combination with care from all formal care providers, that is, care from their general practitioner, home nursing and formal home assistance. Class 6 consisted of older people who were more likely to combine informal care from their family (both nuclear and extended) with formal care from all formal care providers. Finally, two classes of care use consisted of older adults who were more likely to receive care dominated by formal

caregivers. Class 7 comprised older care recipients who were more likely to receive care from all formal caregivers. Class 8 consisted of older people who were more likely to receive formal home assistance. Furthermore, 3.8% of older adults reported to be in need of care but did not receive it (class 9). They were added as an additional class. Classically, research on patterns of care use within older adults reports on a classical mix of the use of formal, informal and the combination of formal and informal care (Broese van Groenou et al., 2016; Gannon and Davin, 2010;.Suanet et al., 2012; Van Houtven and Norton, 2004; Wimo et al., 2017). **Study 1** adds to the literature by showing a more diversified and detailed pattern of care combinations (than the three classical types) delivered by different combinations of a broad range of informal and formal care providers. In this optic, **study 1** gave insight into the complexity of the care mix among community-dwelling older adults. Within **study 2** frail community-dwelling older adults reported their experiences concerning the use of a broad range of formal care and support services going beyond pure healthcare services but also concerning formal home assistance, social housing, cleaning aids, etc. This is in line with research of Hoeck et al. (2012) on the health- and homecare utilisation of frail older adults in Belgium.

In terms of socio-demographic characteristics, **study 1** revealed that people who used formal care of all possible caregivers were more often older, while people who were using informal caregivers were more likely to be younger. Research by Chapell and Blandford (1991) has already stated that, in the first instance, older people use their informal network to deal with their care needs and then progressively use formal care as they become older, face higher needs or when an informal network is lacking. Habib et al. (1993) also came to the conclusion that when older people live alone, the formal system replaces the family. The results on research on the relation between socio-economic characteristics (level of education and income) are less consistent. First, on the one hand **study 1** demonstrated there was no significant relation with the use of formal care. This seems to underline the fact that Belgium has a high-performing and accessible healthcare system. On the other hand, **study 2** indicates that several frail community-dwelling older adults report 'affordability' as an important barrier to access formal care and support services. Also 'awareness', referring to limited health related literacy to be able to find the way in the complex Belgian healthcare structures was stated as a barrier. Second, although people with lower monthly household incomes do not experience barriers in accessing *formal* care, they seem to lack *informal* care and support **(study 1)**. Older people who benefited from informal care were more often higher educated and had a higher monthly household income, while older adults who only received different forms of formal care more often had the lowest incomes. This leads to the determination that elevated social capital seems to be related to economic capital among older adults. Finally, **study 1** also indicates that there were still a certain number of older people (3.8% of the study sample) who indicated that they were in need of care and

support but did not receive it from anyone. This is in line with previous research of De Witte et al. (2010) concerning care shortages in later life. A remarkable feature is that this group of people does not seem to have a lower socio-economic status.

6.1.2. Research question 2

What are the main barriers frail, community-dwelling older adults experience in accessing formal care and support (services) and how can access be improved?

The second research question aimed to explore main barriers frail community-dwelling older adults experience in accessing formal care and support (services) and how access can be improved. **Study 2** detected barriers frail community-dwelling older adults experienced to access formal care and support services using the 5 A's of access to care from Penchansky and Thomas (1981) as they are described by Wyszewianski (2002) and the 6th A (awareness) as added by Saurman (2016) together resulting in a new framework of '6 A's of access to care and support' (accessibility; affordability; availability; acceptability; adequacy (or accommodation). **Study 2** brings to attention that the framework of Penchansky and Thomas can be confidently used to detect access barriers to care and support services in the setting of older adults that live at home. This is an important given, because the framework of Penchansky and Thomas has been frequently used in a broader context of access to services (United Nations Educational, Scientific and Cultural Organisation, 2013), for example to discover access barriers to healthy food (Usher, 2015; Zhang, 2017), access to energy security (Cherp and Jewell, 2014) and access to education (Lee, 2016); but not yet in the frame of older adults and homecare. **Study 2** indicates as well that (despite all policy measures) access to a broad spectrum of care and support services remains a challenge for older people in Belgium. The respondents' barriers concern: 'affordability' referring to a lot of Belgian older adults having limited pensions, 'accessibility' going beyond geographical accessibility but also concerning waiting lists, 'availability' referring to the lack of having someone around, 'adequacy' addressing the insufficiency of motivated staff, the absence of trust in care providers influencing 'acceptability' and 'awareness' referring to limited health literacy. Through the analysis, a 7th barrier (a 7th A) within the results, namely *'ageism'*, was discovered.

The respondents' barriers to access care and support go beyond solely medical services; they also involve the availability of having someone around when they are in need, waiting lists, the price of housing modifications or home automation systems, etc. Within the stories of older respondents, there were also experiences of different aspects of access interfering or relating to each other, for example 'affordability' being interconnected with 'accessibility', when not meeting conditions applied by local governments to enter social housing. Despite the results on income and care use in **study 1**,

the respondents within **study 2** clearly indicated that, although the concept of access goes much further than 'affordability', the financial aspect was often mentioned referring to a lot of Belgian older adults having limited resources and low pensions (Litwin and Sapir, 2009) and seems to remain the most important barrier within Penchansky and Thomas' framework. Also, the limited health literacy of older respondents and the complex Belgian State structure make it extremely difficult for people entitled to apply for financial contributions. This is why **study 3** aimed to give an overview of all incomes and expenditures of older adults with care needs living at home in order to evaluate the affordability of care and support for community-dwelling older adults.

Concerning the improvement of access, the interviews within **study 2** clearly showed that improving one barrier might have a positive impact on (an)other barrier(s) as well. In this context, and older man with physical disabilities for example mentioned that moving to a cheaper adapted apartment on the ground floor made it easier for providers to physically reach him or another man mentioned that moving to better isolated housing decreased heating costs.

6.1.3. Research question 3

What are the biggest expenditures of community-dwelling older adults and which costs are important in causing financial difficulties?

The third research question identified the biggest expenditures of community-dwelling older adults and which costs are important in causing financial difficulties. **Study 3** provided an overview of all expenditures within a household in one month: housing expenditures, living expenditures (e.g. nourishment, clothes), leisure expenditures, expenditures on medical material, medical care expenditures, welfare expenditures (i.e. family caregiving, household support (providing assistance with cooking, groceries, cleaning, some ADL and IADL tasks, keeping the older adult company) as well as meals on wheels, chores, cleaning aids, etc.), and expenditures on informal care. Housing and living expenditures showed to be the biggest expenditures followed by leisure expenditures, welfare expenditures, expenditures on medical material and medical care expenditures.

Although **study 1** indicated that socio-economic status has no significant relation with the access and use of formal services, **study 3** conclusion points out that welfare expenditures (e.g. domestic aid, meals on wheels, etc.) take a high proportion in the expenditures of older adults. This is because in Belgium these welfare services are coordinated by the Regional authorities and not reimbursed by the national health insurance (in contrast with for example home nursing); they need to be paid for on an hourly basis or per prestation according to the income (Claessens et al., 2011; Van der Gucht 2016;

Flemish Living and Care Decree of 13 March 2009). Consequently, welfare services have another status than medical care services in Belgium and are often considered financially less accessible (Cès et al., 2016). This is also confirmed by the experiences of older adults within **study 2** stating that for example the high cost of housing modifications, for which the government is not or only a limited percentage contributing concern an 'affordability' barrier. In addition, although a big part of medical care interventions in Belgium is reimbursed, the cost of medical material is often not included in this reimbursement and has to be provided by the client itself which resulted in high expenditures on medical material (Royal Decree nr. 78 of 10 November 1967).

Study 3 indicates that almost one out of three participants within the research declared to experience difficulties to make ends meet (to have financial difficulties to pay for all costs) at the end of the month. This is a large percentage compared to the percentage of Belgian older adults being at risk of poverty (17.4%) (Statbel, 2017). Financial compensations and contributions are often a necessary part of the regular income to make the ends meet. In Flanders, some compensations (for example the Flemish Care Insurance), although also designed to support and validate the informal caregiver, are paid directly to the person with care needs and used as a necessary supplementary income (Bronselaer et al., 2016). It is generally demonstrated that residential care facilities for older adults are very expensive (on average €56.30/day in 2017) (Van den Bosch, 2016, Vlaams Agentschap Zorg & Gezondheid, 2018), but this **study 3** highlights that living at home with care needs also costs a lot of money.

6.1.4. Research question 4

What can be the added value of a follow-up process after preventive home visits within community-dwelling older adults to increase *sustainable* access to care and support? And how can this follow-up be organised?

The fourth research aimed to identify the added value of a follow-up process after preventive home visits within community-dwelling older adults in order to increase sustainable access to care and support and how this follow-up can be organised.

Study 2 highlights that some older adults gave up on applying for services because of access problems. In this context, an older man stated that he turned town his application for a cleaning aid because there was a waiting list of six months. This is in line with research with research of Cyclus and Papanicolas (2015) stating that long waiting times are an important access barrier within public care systems in Europe not only affecting low-income groups. Within **study 4**, we explored to which extent telephonic follow-up has an added value within the D-SCOPE detection and prevention program for

frail community-dwelling older adults. Telephonic follow-up has already proven to be a(n) (cost-) effective strategy for providing comfort and timely referral for older adults after hospital discharge and to prevent hospital readmissions (Kirk, 2014; Lewis et al.,2017). Research also points out that telephonic follow-up improves the patients' satisfaction after hospital discharge (Braun et al., 2009; Guss et al., 2013).

Study 4 brings to attention that follow-up telephone calls after preventive home visits have a substantial added value for older adults, formal caregivers and informal caregivers and can have a potential role in detecting care shortages. The social aspect and involvement were mentioned by these three groups as a positive aspect within the telephone-program. Professional caregivers underlined the potential of such telephones to identify unmet needs while informal caregivers appreciated the ability on reducing informal caregivers' burden. Within our ageing society, where major attention is paid to 'socialisation of care' and the value of volunteers (Degrave and Nyssens, 2010; Dury, 2018), trained volunteers might have a role in telephone follow-up programs, certainly because no special equipment apart from a telephone is needed. Professional caregivers particularly appreciated repeated follow-up calls as an effective strategy to identify unmet needs that were not mentioned during preventive home visits. This is of importance because **study 1** indicates that 3.8% of community-dwelling older adults who indicate they are in need of care are not receiving it. In the existing literature on preventive home visits, there is no consensus on their effectiveness of providing the ability of independent living to older adults (Mayo-Wilson et al., 2014). The results of **study 4** bring under attention that a repeated telephone follow-up program after preventive home visits might give better results on frail older adults' ability to age in place. Although it was not initially the purpose, some informal caregivers also received follow-up telephones. They clearly mentioned their appreciation stating that they felt supported and it gave them the ability to receive more information about the older adult they cared for, information that they could not receive directly from the older adult.

6.2. Dissertation' implications for policy and practice

The findings of the present dissertation also provide some recommendations for policy and practice.

6.2.1. Implication 1: a broad approach of care and support is recommended

Study 1 gives insight in the different types of formal and informal care use that can be identified with a broad range of formal and informal care providers involved and also into the complexity of the care mix among community-dwelling older adults including several different combination of informal and formal care use (Fret et al., 2017). **Study 2** gave insight in experiences of community-dwelling older

adults when using a broad range of care and support services. This result also indicates towards policy and practice that a broad definition of 'care and support' is desirable, respecting the diverse care and support mix community-dwelling older adults use. The Flemish Government already made a good start in incorporating a broad description of 'care and support' (as every activity or series of activities in the frame of health- and social care policies) in their new legislation (Flemish government, 2018). It is desirable for professionals to take into account the possible diversity of care and support usage among older adults (going beyond solely medical services but also concerning informal caregivers, welfare services, social housing, meals on wheels, local service centers, etc.) and include all possible partners around the person with care needs, for example in multidisciplinary consultations. Also **study 2** indicates that in order to make care and support more accessible for people in order to be able to age in place, governments and providers could take measures to overcome access barriers and should take into account a broad description of access. As there are several professional caregivers who are visiting older adults on a daily or regular basis, they can have a role in detecting and being aware about access problems and care and support needs that remained undetected. Therefore professional caregivers need to look further than their own profession. The elaborated and tested framework of access to care for frail community-dwelling older adults ('7 A's of access' based on Penchansky and Thomas; Saurman) might help them with that.

Not all four studies included a sample of frail older adults. **Study 1** focused on a sample of older adults that faced care needs and already were using care (both formal and informal). Although, we did not select on frailty within the sample in **study 1**, the prevalence of frailty appeared to be higher than in the reference population in Belgium. **Study 2** included a sample of frail older adults that indicated to be in need of care and support (but experienced difficulties to find access). **Study 3** focused on older adults with extensive care needs and **study 4** focused on older adults who were potentially frail according to the baseline questionnaire. Within a broad approach of care and support, both policymakers and professionals should take into account the complex interplay between frailty, care needs and care demands (to not exclude care avoiders).

6.2.2. Implication 2: create awereness for access barriers

However Belgium is often stated as a good example concerning access to care and support, there are still large inequalities concerning access to care and utilisation (Björnberg, 2017; OECD, 2016). It seems that access to a broad spectrum of care and support services remains a challenge within our ageing society. **Study 2** reports on several access barriers frail community-dwelling older adults are confronted with. One of these barriers concerns 'accessibility' of care and support which is determined

by ‘how easily the client can physically reach the provider’s location’ (Wyszewianski, 2002, p. 1441) or how easily the provider can reach the client. As Belgium is a country that is also affected by busy roads and traffic jams, the distance from provider to client certainly remains an issue (De Decker et al., 2017). Further experiments with community-centered care where care and support is embedded in the living environment of the person with care needs can give an answer to this mobility and distance problem (Bekaert et al., 2016). The Flemish Government has already imbedded community-centered care as a horizontal principle in the preliminary draft of the new decree on living and care facilities (Flemish Government, 2018). However, experiences in **study 2** were not only about geographical accessibility, but also other issues concerning accessibility such as waiting lists. The Flemish Government has done several multiple efforts last years to decrease the waiting lists in the sector op people with disabilities (Persdienst Vandeurzen, 2017); nevertheless results indicate that there are also waiting lists in elderly care, for example several organisations for home nursing or family caregiving already have a client stop in some regions. In line with the broad approach of care and support access, the Flemish Government has launched the concept of ‘Integrated Broad Access’ (i.e. a partnership between at least the social service of the municipality, the center of general welfare work and the social service of the health insurance funds to realise accessible social assistance and services and the prevention of underprotection) (Flemish Government, 2017). Our advice is to keep this ‘access point’ broad in practice and not to limit the collaboration between these 3 partners, but to include all partners that detect access barriers in the field. The elaborated framework with the ‘7A’s of access’ can be helpful for policymakers and organisations to screen for possible access barriers within the development of new legislation or measures.

6.2.3. Implication 3: attention for ‘ageism’ within care and support services

Study 2 identified the presence of ‘ageism’ (i.e. stereotyping and discrimination against individuals and groups on the basis of their age) as a barrier within the experiences of older adults. This presence is in line with research indicating ageism is an important problem limiting access to services among older adults (Robb et al., 2002; Kydd and Fleming, 2015). Research also indicates that ageism stereotypes of older people can have an important impact on older adults physical and mental health and well-being; internalised negative stereotypes can produce self-fulfilling prophecies through stereotype embodiment and contribute to weakness and dependency (Chrisler et al., 2016) Also, more negative ageing self-perceptions by older adults are associated with a higher likelihood of health care delay and perceived barriers to care (Sun and Smith 2017).

A positive vision of ageing should be promoted among formal and informal caregivers. Governments might contribute to that with the financing of sensitizing campaigns. Furthermore, training for

professionals within healthcare organisations can contribute in shaping positive attitudes towards older adults.

6.2.4. Implication 4: automatic entitlement for all social rights and benefits

Study 3 points out financial compensations and contributions are often a necessary addition to the regular income of older adults with care needs to make the ends meet. Research indicates however that there is a considerable non-take up of social rights and benefits in Belgium, also among older adults (De Vil and Van den Bosch, 2013; Van Mechelen and Janssens, 2017). Considering the fact that in the frame of the sixth Reform of the State of 2014, the competences on elderly care from the Federal State are transferred to the Regional Governments and that this transfer is still ongoing, it would be a good momentum for all responsible governmental entities to make agreements about automatic entitlements for all financial compensations and contributions and broader all social rights. Further experiments with automatic entitlements can overcome access barriers to services for people with limited 'awareness' and health related literacy. In recent years, a project to proactively entitle a higher reimbursement status for medical care to people with low incomes already showed promising results and pointed out that automatic entitlement might be an effective strategy to improve the access to different kinds of services (Goedemé et al., 2017; Van Gestel et al., 2017).

6.2.5. Implication 5: permanent attention for the 'affordability' of care and support services

'Affordability' was mentioned by older adults within **study 2** as an highly important barrier older adults face to access care and support services. Also **study 3** provides more insight in the 'affordability' barrier by the analysis of expenditures of community-dwelling older adults concluding that living at home with care needs is expensive. Research indicates that out-of-pocket payments are rather high in Belgium, especially for non-hospital care (OECD, 2016). The Flemish Government has already made a start to reduce the affordability barrier with the introduction of the 'Flemish Social Protection' providing a 'free to spend care budget' for older and dependent people, but it remains unclear which implications the future person-centered financing system in elderly care shall have on the financial situation of older adults with care needs as in the sector of people with disabilities there were already several uncertainties on which costs could be paid with the 'care budget' (Flemish Government, 2018; Woolham et al., 2017). Therefore, when providing direct payments and personal budgets to older adults with care needs, simple and clear criteria of use are advised. As **study 3** indicates that welfare costs take a big proportion in the budget of older adults and are a risk of causing financial difficulties,

a system of 'maximal invoice for social care' as it already exists and has proven to be effective for medical care would provide would be good and is needed (Pacolet et al., 2013). This idea has already been posed by several Flemish Ministers competent for homecare recognizing that the cost for several support services which have to be paid for on an hourly basis according to the income of the client can have a high impact.

6.2.6. Implication 6: recognise the added value of follow-up

Study 4 concludes that follow-up telephone calls can be an effective and innovative strategy after preventive home-visits for community-dwelling older adults providing also valuable support for the informal caregiver. Within the important 'socialisation of care' tendency, trained and supported volunteers could have a role in follow-up as it was suggested by a professional caregiver participating in **study 4.** Also, the sector of home nursing has submitted several propositions towards the National Institute for Health and Disability Insurance (NIHDI) to provide a structural financing for follow-up visits within highly frail older adults (Paquay, 2018). Research indicates that preventive home visit programs including follow-up visits especially have a favorable effect among younger subjects in improving autonomy (Pröfener, 2016). Other research points out the valuable role of preventive home visits and follow-up in health promotion (Behm et al., 2013). Since the sixth Reform of the State, the Flemish Government is entirely competent for the financing of preventive health initiatives and could take initiatives in the financing of preventive follow-up programs within older adults to detect unmet needs.

6.3. Limitations of the dissertation and directions for future research

This dissertation also has some limitations and some challenges for future research can be identified.

6.3.1. Future challenge 1: the role of the informal caregiver

The present doctoral dissertation aimed to explore which are the conditions to organise and provide access to high-quality care and support for (frail) community-dwelling older adults. Within our studies, we focused mainly on formal care and support. We acknowledge that also the informal caregiver has a central role important within the care and support process (Criel et al., 2014; Desmedt et al., 2017). This was confirmed by the types of care use developed in **study 1** indicating that a high percentage of older adults only received help from informal caregivers and by the experiences of **study 2** where experiences of older adults indicated the lack of informal caregivers as an access barrier. Moreover, within the 'socialisation of care' policy, the role of informal care and 'care through the community' is

only increasing (De Donder et al., 2017). Future research can contribute to the exploration of the role informal caregivers can have in reducing access barriers or how follow-up programs can reduce informal caregivers' burden.

6.3.2. Future challenge 2: reducing access barriers

The Penchansky and Thomas' framework has proven to be effective and efficient in identifying several access barriers. This is efficiency is confirmed by the earlier use of the framework to detect access barriers to different kinds of services, for example to discover access barriers to healthy food (Usher, 2015; Zhang, 2017), access to energy security (Cherp and Jewell, 2014) and access to education (Lee, 2016). As this is the first time this framework has been used in the context of older adults and homecare, further research should be conducted to determine whether all barriers community-dwelling older adults experience were covered. It would also be particularly interesting to explore if any barriers were more important to those with different types of frailty, or who were frail across a greater number of domains as we focused in **study 2** on a general population of frail community-dwelling older adults. Also, it would be good to focus in future research on good examples of highly accessible services to gain inspiration on how services can be organised in an efficient way.

6.3.3. Future challenge 3: health literacy and coordination between policy levels and legislation

The sixth Reform of the State has transferred a numerous amount of competences and budget from Federal State to the regional authorities. As it is not yet clear how this transfer of budget and competences will be translated in concrete policy for the regional levels (this is the fact for the Flemish, Brussels, Walloon and German Region), this and other reforms (such as Integreo, primary healthcare reform, etc.) cause high levels of insecurity among care professionals in the whole Belgian country. More coordination between these policy levels will certainly be needed to provide clarity for professionals and care seekers. The challenges according to find appropriate services have been pointed out by **study 3.** In the new Flemish legislation the term 'care and support request' is used to define "the need for care and support that a person or his environment feels or that is objectively determined" (Flemish Government, p. 2). This contains some risks, because it implies that every person in need for care and support has the ability and literacy to express this need and this description also excludes 'care avoiders'. Furthermore, the results of **study 2** report experiences of older adults with limited health literacy not finding their way to appropriate services. Research revealed that advanced age might result in a significant increase in the prevalence of inadequate health literacy which demands

for a tailored approach (Zamora and Clingerman, 2011; Manofo and Wong, 2012). Although, several competences are now entitled to the Flemish Government, a permanent coordination with the Federal level is highly important. For example, both Federal and Flemish Government both use the concept of 'case manager' in new legislation, but with a different description That does not foster access for people in need of care and support. Attention in both policy and future research should be paid to this coherence between policy levels and the possibility for older adults to find their way.

6.3.4. Future challenge 4: the essential role of follow-up

As the follow-up telephones in **study 4** have been conducted during a limited period within a definite project, further research is desirable to identify their most effective way of organisation as existing research still indicates a lack of consensus on how effective follow-up programs should be conducted (Mayo-Wilson et al. 2014; Vass et al. 2004). Certainly, after the sixth Reform of the State (2014), the Belgian care and support sector is in full transition (as in other parts of Europe) with numerous new legislation being developed. This study provided a first exploratory research, further research could provide evidence on how follow-up after preventive home visits can be implemented in practice and policy and further validate the essential role of follow-up in reducing drop-out from care.

6.4. General conclusion

The present doctoral dissertation aimed to explore which are the conditions to organise and provide access to this high-quality care and support for (frail) community-dwelling older adults.

This dissertation provides insight in the variety of care and support use among community-dwelling older adults.

The developed framework is applicable to detect access barriers to a broad range of care and support services within community-dwelling older adults concerning barriers of accessibility; affordability; availability; acceptability; adequacy (or accommodation), awareness and ageism, which could easily be used by both professional and informal caregivers.

This doctoral dissertation provides insight in the expenditure pattern of community-dwelling older adults and provided information on which costs take the highest share within the budget of older adults. Also this research provides evidence on the high cost of living at home with care needs.

This dissertation also points out that follow-up telephones can be an innovative and cost-effective strategy to increase sustainable access to care and support and detect unmet care needs and also have an added value towards professionals and informal caregivers.

References

Behm, L., Ivanoff, S. D. and Zidén, L. (2013). Preventive home visits and health–experiences among very old people. *BMC public health*, *13*(1), 378.

Björnberg, A. (2017). Euro Health Consumer Index 2016. Report. Marseillan: Health Consumer Powerhouse.

Braun, E., Baidusi, A., Alroy, G. and Azzam, Z.S. (2009). Telephone follow-up improves patients satisfaction following hospital discharge. *European journal of internal medicine, 20*(2), 221-25.

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

Bronselaer, J., Vandezande, V., Vanden Boer, L., & Demeyer, B. (2016). Sporen naar duurzame mantelzorg. Hoe perspectief bieden aan mantelzorgers. Brussel: Departement Welzijn, Volksgezondheid en Gezin, 1-405.

Broese van Groenou, M., Glaser, K., Tomassini, C. and Jacobs, T. (2006). Socioeconomic status differences in older people's use of informal and formal help: a comparison of four European countries. *Ageing & Society*, *26*(5), 745–66.

Cès, S., Flusin, D., Schmitz, O., Lambert, A.S., Pauwen, N and Macq, J. (2016). Mantelzorgers van thuiswonende ouderen in België: een cruciale en complexe rol. Brussel: Koning Boudewijnstichting, 1-146.

Chappell, N. and Blandford, A. (1991) Informal and formal care: exploring the complementarity. *Ageing and Society, 11*(3), 299–317.

Cherp, A. and Jewell, J. (2014). The concept of energy security: Beyond the four As. *Energy Policy*, *75*, 415-21.

Chrisler, J. C., Barney, A. and Palatino, B. (2016). Ageism can be hazardous to women's health: Ageism, sexism, and stereotypes of older women in the healthcare system. *Journal of Social Issues*, *72*(1), 86-104.

Claessens, E., Vertriest, S., Vandijck, D. and Petrovic, M. (2011). Gezondheidseconomische evaluatie van mantelzorg bij (zwaar) zorgafhankelijke ouderen in de thuiszorg. Gent: Universiteit Gent.

Criel, B., Vanlerberghe, V., De Koker, B., Decraene, B., Engels, E. and Waltens, R. (2014). Informal home care for elderly in Belgium: A study on the Features and challenges of informal care at local level. *Community mental health journal*, *50*(7), 848-853.

Cylus, J. and Papanicolas, I. (2015). An analysis of perceived access to health care in Europe: How universal is universal coverage?. *Health policy*, *119*(9), 1133-144.

De Decker, P., Vandekerckhove, B., Wellens, C., Volckaert, E., & Schillebeeckx, E. (2017). Vergrijzing op het platteland. Samenvatting en aanbevelingen. Brussel: Vlaamse Landmaatschappij.

De Donder, L., De Witte, N., Verté, D., Dury, S., Buffel, T., Smetcoren, A.S., Brosens, D. and Verté, E. (2014). Developing evidence-based age-friendly policies: a participatory research project, in *SAGE Research Methods Cases*, (pp. 9-14). London: Sage Publications.

De Donder, L., Smetcoren, A.-S., Dury, S., Van Regenmortel, S., Lambotte, D., Duppen, D., Fret, B., Brosens, D., De Witte, N. and Verté, D. (2017). Zorginnovatie in Vlaamse proeftuinen: Onderzoek naar Actief Zorgzame Buurten in Brussel en Antwerpen. Brussel: Belgian Ageing Studies.

Degavre, F. and Nyssens, M. (2010). Care as a Social Construct: The Case of Home Care Workers in Contemporary Belgium', in T. Addabbo, M.P. Arrizabalaga, C. Borderías and A. Owens (eds.). *Gender Inequalities, Households and the Production of Well-Being in Modern Europe,* (pp. 145-62). London: Routledge.

Desmedt, M., Bergs, J., Vertriest, S., Hellings, J., Petrovic, M. and Vandijck, D. (2017). Mantelzorg: een literatuurstudie en simulatiemodel betreffende de economische waarde en de financiële impact op de ziekteverzekering. *Tijdschrift voor Geneeskunde*, *73*(23), 1473-480.

De Vil, G. and Van den Bosch, K. (2013). Working Paper 06-13-De evolutie van de armoede bij ouderen nader bekeken. Brussels: Federal Planning Bureau.

De Witte, N., Buffel, T., De Donder, L,. Dury, S. and Verté, D. (2010). Care shortages in later life: the role of individual and contextual variables in Flanders, Belgium. *International Journal of Social Sciences and Humanity Studies*, *2*(1), 111-18.

Dury, S. (2018). Dynamics in motivations and reasons to quit in a Care Bank: a qualitative study in Belgium. *European Journal of Ageing*, 1-10.

Flemish Government (2017). Preliminary draft of decree concerning local social policy. Brussels: Flemish Government.

Flemish Government (2018). Decree on Flemish social protection. Brussels: Flemish Government.

Flemish Government (2018). Preliminary draft of decree concerning the organisation of primary care, the regional care platforms and the support of the primary care providers. Brussels: Flemish Government.

Flemish Government (2018). Preliminary draft of decree concerning living and care facilities. Brussels: Flemish Government.

Flemish Living and Care Decree 13 March 2009, Besluit van de Vlaamse Regering betreffende de programmatie, de erkenningsvoorwaarden en de subsidieregeling voor woonzorgvoorzieningen en verenigingen van gebruikers en mantelzorgers. Vlaamse Gemeenschap: Brussel.

Fret, B., Lambotte, D., Van Regenmortel, S., Dury, S., De Witte, N., Dierckx, E., De Donder, L., Verté, D. and D-SCOPE Consortium (2017). Socio-demographic, socio-economic and health need differences between types of care use in community-dwelling older adults. *International Journal of Care and Caring*, 1(3), 351–66.

Gannon, B. and Davin, B. (2010). Use of formal and informal care services among older people in Ireland and France. *The European Journal of Health Economics*, *11*(5), 499–511.

Goedemé, T., Van Gestel, R., Janssens, J., Lefevere, E., Lemkens, R., & De Spiegeleer, T. (2017). De proactieve flux: een succesvolle manier om de opname van de verhoogde tegemoetkoming te verbeteren. [The proactive flux: a successfull way to improve the uptake of the higher reimbursement status]. *CM-Informatie, (270),* 19-25.

Guss, D.A., Leland, H. and Castillo, E.M. (2013). The impact of post-discharge patient call back on patient satisfaction in two academic emergency departments. *The Journal of emergency medicine, 44*(1), 236-41.

Habib, J., Sundstrom, G. and Windmiller, K. (1993). Understanding the pattern of support for the elderly: a comparison between Israel and Sweden. *Journal of Aging & Social Policy, 5*(1/2), 187–206.

Hoeck, S., François, G., Geerts, J., Van der Heyden, J., Vandewoude, M. and Van Hal, G. (2011). Health-care and home care utilization among frail elderly persons in Belgium. *European Journal of Public Health, 22*(5), 671–6.

Kirk, C. (2014). Routine telephone follow-up of older people after hospital admissions. *Current Ageing Science, 7*(2), 143-54.

Kydd, A and Fleming, A. (2015). Ageism and age discrimination in health care: Fact or fiction? A narrative review of the literature. *Maturitas*, *81*(4), 432-438.

Lee, J. (2016). Paying for School Choice: Availability Differences among Local Education Markets. *International Journal of Education Policy and Leadership*, 1*1*(5), n5.

Lewis, E., Samperi, S. and Boyd-Skinner, C. (2017). Telephone follow-up calls for older patients after hospital discharge. *Age and ageing, 46*(4), 544-46.

Litwin, H. and Sapir, E. (2009). Perceived Income Adequacy Among Older Adults in 12 Countries: Findings From the Survey of Health, Ageing, and Retirement in Europe. *The Gerontologist, 49*(3), 397-406.

Manafo, E. and Wong, S. (2012). Health literacy programs for older adults: a systematic literature review. *Health Education Research*, 27(6), 947-960.

Mayo-Wilson, E., Grant, S., Burton, J., Parsons, A., Underhill, K. and Montgomery, P. (2014). Preventive home visits for mortality, morbidity, and institutionalization in older adults: a systematic review and meta-analysis. *PloS one, 9*(3). DOI: https://doi.org/10.1371/journal.pone.0089257.

Organisation for Economic Cooperation and Development (OECD) (2016). Health policy in Belgium http://www.oecd.org/belgium/Health-Policy-in-Belgium-February2016.pdf. Accessed 10 October 2018.

Pacolet, J., De Coninck, A and De Wispelaere, F. (2013). Financiering van de thuiszorg: het perspectief van de voorzieningen. Leuven: Steunpunt Welzijn, Volksgezondheid en Gezin.

Paquay, L. (2018). Het 'Preventief en/of opvolgingsbezoek (POB) in de thuisverpleging'. Brussel: VFDT.

Penchansky, R. and Thomas, J. (1981). The Concept of Access: definition and relationship to consumer satisfaction. *Medical Care, 19*(2), 127-40.

Persdienst Vaneurzen (2018). Vlaamse Regering investeert in 2018 €72 miljoen extra in meer zorggarantie voor personen met een handicap. Brussel: persdienst Vandeurzen.

Pröfener, F., Anders, J., Dapp, U., Minder, C.E. and Golgert, S. (2016). Acceptance of preventive home visits among frail elderly persons: Participants an non-participants in a Follow-up after 2 and 4 years within the LUCAS longitudinal study. *Zeitschrift fur Gerontologie und Geriatrie*, *49*(7), 596-605.

Royal Decree nr. 78 of 10 November 1967. Koninklijk besluit nr. 78 betreffende de uitoefening van de gezondheidszorgberoepen. Federale Overheid: Brussel.

Robb, C., Chen, H. and Haley, W. E. (2002). Ageism in mental health and health care: A critical review. *Journal of Clinical Geropsychology*, *8*(1), 1-12.

Saurman, E. (2016). Improving access: modifying Penchansky and Thomas's Theory of Access. *Journal of Health Services Research & Policy*, *21*(1), 36-39.

Statbel (2017). Armoede-indicatoren in België in 2016 (EU-SILC). https://statbel.fgov.be/nl/themas/huishoudens/armoede-en levensomstandigheden/armoederisico#news. Accessed 4 October 2018.

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

Sun, J.K. and Smith, J. (2017). Self-perceptions of aging and perceived barriers to care: Reasons for health care delay. *The Gerontologist*, *57(suppl_2),* 216-26.

United Nations Educational, Scientific and Cultural Organisation (UNESCO) (2013). Opening new avenues for empowerment: ICTs to access information and knowledge for persons with disabilities. http://unesdoc.unesco.org/images/0021/002197/219767e.pdf. Accessed 1 October 2018.

Usher, K.M. (2015). Valuing all knowledges through an expanded definition of access. *Journal of Agriculture, Food Systems, and Community Development*, *5*(4), 109-14.

Van den Bosch, K. (2016). Measuring social protection for older people with long-term care needs in Belgium. A report on the completion of an OECD data collection questionnaire. https://www.plan.be/admin/uploaded/201609011418490.REP_LTCOECD062016_11305.pdf. Accessed 4 October 2018.

Van Gestel R., Goedemé, T., Janssens, J., Levefere, E. and Lemkens, R. (2017). A Reminder to Pay Less for Healthcare: take-up of Increased Reimbursement in a large-scale randomized field experiment. *Herman Deleeck Centre for Social Policy Working Paper, 17*(12), 1-36.

Van Mechelen, N. and Janssens, J. (2017). Who is to blame? An overview of the factors contributing to the non-take-up of social rights. *Herman Deleeck Centre for Social Policy Working Paper, 17*(08), 1-32.

Van Mechelen N. and Van Der Heyden M. (2017). De strijd tegen non-take up: een inventaris van beleidsmaatregelen en reflectie in het licht van wetenschappelijke literatuur en beleidservaringen in het VK en Zweden. TAKE Policy Brief Nr. 1/2017. Antwerpen: Universiteit Antwerpen.

Van Houtven, C. H. and Norton, E. C. (2004). Informal care and health care use of older adults. *Journal of health economics*, *23*(6), 1159-180.

Vass, M., Avlund, K., Kvist, K., Hendriksen, C., Andersen, C.K. and Keiding, N. (2004). Structured home visits to older people. Are they only of benefit for women? A randomised controlled trial. *Scandinavian Journal of Primary Health Care*, *22*(2), 106-11.

Vlaams Agentschap Zorg & Gezondheid (2018). Hoeveel bedraagt de gemiddelde dagprijs in uw woonzorgcentrum? Meting 2017. https://www.zorg-en-gezondheid.be/dagprijzen. Accessed 4 October 2018.

Wimo, A., Elmståhl, S., Fratiglioni, L., Sjölund, B. M., Sköldunger, A., Fagerström, C., Berglund, J. and Lagergren, M. (2017). Formal and informal care of community-living older people: A population-based study from the Swedish National study on Aging and Care. *The journal of nutrition, health & aging*, *21*(1), 17-24.

Woolham, J., Daly, G., Sparks, T., Ritters, K., & Steils, N. (2017). Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment. *Ageing & Society*, 37(5), 961-984.

Wyszewianski, L. (2002). Access to Care: Remembering Old Lessons. *Health Services Research, 37*(6), 1441–443.

Zamora, H. and Clingerman, E. (2011). Health Literacy Among Older Adults. *Journal of Gerontological Nursing*, 37(10), 41-51.

Zhang, M. (2017). A Geographical Analysis of Food Access in the Greater Hartford Area of Connecticut. (Doctoral dissertation). University of Connecticut Graduate School.

List of publications and contributions

Publications in scientific journals with an international referee system

Dury, S., De Roeck, E., Duppen, D., **Fret, B**., Hoeyberghs, L., Lambotte, D., Van der Elst, M., van der Vorst, A., Schols, J., Kempen, G., Rixt Zijlstra, G., De Lepeleire, J., Schoenmakers, B., Kardol, T., De Witte, N., Verté, D., De Donder, L., De Deyn, P., Engelborghs, S., Smetcoren, A. and Dierckx, E. (2016). Identifying frailty risk profiles of home-dwelling older people: focus on sociodemographic and socioeconomic characteristics. *Aging & Mental Health, 21*(10), 1031-103. doi: 10.1080/13607863.2016.1193120.

Fret, B., Lambotte, D., Van Regenmortel, S., Dury, S., De Witte, N., Dierckx, E., De Donder, L., Verté, D. and D-SCOPE Consortium (2017). Socio-demographic, socio-economic and health need differences between types of care use in community-dwelling older adults. *International Journal of Care and Caring*, 1(3), 351–66. DOI: https://doi.org/10.1332/239788217X15027193795897.

Smetcoren, A. S., Dury, S., De Donder, L., Dierckx, E., De Witte, N., Engelborghs, S., De Deyn, P.P., van der Vorst, A., Van der Elst, M.J.M., Lambotte, D.F., Hoeyberghs, L.J., **Fret, B.**, Duppen, D., De Roeck, E.E., Kardol, M.J.M., Schoenmakers, B., De Lepeleire, J., Zijlstra, G.A.R., Kempen, G.I.J.M., Schols J.M.G.A. and Verte, D. (2017). Detectie en preventie van kwetsbaarheid: Op zoek naar risicoprofielen voor fysieke, psychische, sociale en omgevingskwetsbaarheid. *Tijdschrift voor Gerontologie en Geriatrie*, *13*(78), 1-11.

Dury, S., Dierckx, E., van der Vorst, A., Van der Elst, M., **Fret, B.**, Duppen, D., Hoeyberghs, L., De Roeck, E., Lambotte, D.F., Smetcoren, A-S., Schols, J.M.F.A., K, Kempen, G.I.J.M., Zijlstra, G.A.R., De Lepeleire, J., Schoenmakers, B., Verte, D., De Witte, N., Kardol, M.J.M., De Deyn, P.P., Engelborghs, S. and De Donder, L. (2018). Detecting frail, older adults and identifying their strengths: results of a mixedmethods study. *BMC Public Health*, *18*(1), 191. doi: 10.1186/s12889-018-5088-3.

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

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

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

Lambotte, D. F., Kardol, M. J. M., Schoenmakers, B., **Fret, B.**, Smetcoren, A. S., De Roeck, E., Van der Elst, M., De Donder, L. and D-SCOPE Consortium (2018). Relational aspects of mastery for frail, older adults: The role of informal caregivers in the care process. *Health & Social Care in the Community*, *2018*, 1-10.

Fret, B., Mondelaers, B., De Donder, L., Switsers, L., Smetcoren, A-S., Verté, D. and D-SCOPE Consortium (2018). Exploring the cost of 'ageing in place': expenditures of community-dwelling older adults in Belgium. *Ageing International*. https://doi.org/10.1007/s12126-018-9341-y.

Vulgarising publications

De Donder, L., **Fret, B.** and Mondelaers, B. (2016). Zorginnovatie in Vlaamse proeftuinen: Losse eindjes: Zorguitgaven van kwetsbare, thuiswonende ouderen. Brussel: Belgian Ageing Studies.

De Donder, L., Smetcoren, A.-S., Dury, S., Van Regenmortel, S., Lambotte, D.F., Duppen, D., **Fret, B.**, Brosens, D., De Witte, N. and Verte, D. (2017). *Zorginnovatie in Vlaamse proeftuinen: Onderzoek naar Actief Zorgzame Buurten in Brussel en Antwerpen.* Brussel: Belgian Ageing Studies.

Personal communications at conferences as 1st author (national and international) (2014-2018)

Fret, B. et al. (2015). Socio-demographic and socio-economic profiles of community-dwelling older adults by the type of care use. Symposium presentation at: 45th BSG conference, Stirling, UK.

Fret, B. et al. (2016). Socio-demographic characteristics and care use patterns in community-dwelling older adults. Poster presentation at: 39th Wintermeeting of Gerontology and Geriatrics, Oostende, Belgium.

Fret, B. et al. (2017). Early detection of frailty in community-dwelling older adults by preventive home visits: an intervention study. Symposium presentation at: 21st IAGG World Congress of Gerontology and Geriatrics, San Fransisco, USA.

Fret, B. et al. (2018). D-SCOPE detectie en preventieprogramma voor kwetsbare thuiswonende ouderen. Individual presentation at: 44ste Week van de Verpleging NVKVV, Oostende.

Fret, B. et al. (2018). Access to care of frail community-dwelling older adults. Symposium presentation at: 47th BSG conference, Manchester, UK.

Fret, B. et al. (2018). Access to care of frail community-dwelling older adults. Symposium presentation at: 70th GSA Annual Scientific Meeting, Boston, USA.

Contributions co-authors different PhD articles

Manuscript published as Fret, B**.**, Lambotte, D., Van Regenmortel, S., Dury, S., De Witte, N., Dierckx, E., De Donder, L., Verté, D. and D-SCOPE Consortium (2017). Socio-demographic, socio-economic and health need differences between types of care use in community-dwelling older adults. *International Journal of Care and Caring*, 1(3), 351–66. DOI**:** https://doi.org/10.1332/239788217X15027193795897.

Bram Fret: primary author and researcher, coordinating and conducting LCA analysis (identifying types of care use in cooperation with Deborah Lambotte), reading and writing literature, writing introduction, data and methods, results and discussion, conclusion

Deborah Lambotte: cooperation in LCA analysis (identifying types of care use), feedback on the manuscript

Sofie Van Regenmortel: expertise in LCA analysis, feedback on the manuscript

Sarah Dury: expertise in statistical analysis, feedback on the manuscript

Nico De Witte: feedback on the manuscript

Eva Dierckx: feedback on the manuscript

Liesbeth De Donder: feedback on research design and statistical analysis and feedback on the complete manuscript

Dominique Verté: feedback on research design, analysis and feedback on the complete manuscript

Manuscript accepted: Fret, B., De Donder, L., Lambotte, D., Dury, S., Van der Elst, M, De Witte, N., Switsers, L., Hoens, S., Van Regenmortel, S., Verté, D. and D-SCOPE Consortium (2018). Access to care of frail community-dwelling older adults in Belgium: a qualitative study. *Primary Healthcare Research & Development*.

Bram Fret: primary author and researcher, coordinating and conducting qualitative analysis, reading and writing literature, writing introduction, data and methods, results and discussion, conclusion

Liesbeth De Donder: feedback on research design, peer debriefing qualitative analysis and feedback on the complete manuscript

Deborah Lambotte: peer debriefing qualitative analysis and feedback on the manuscript

Sarah Dury: feedback on the manuscript

Michaël Van der Elst: feedback on the manuscript

Nico De Witte: feedback on the manuscript

Lise Switsers: feedback on the manuscript

Sylvia Hoens: feedback on the manuscript

Sofie Van Regenmortel: feedback on the manuscript

Dominique Verté: feedback on research design, analysis and feedback on the complete manuscript

Manuscript published as Fret, B., Mondelaers, B., De Donder, L., Switsers, L., Smetcoren, A-S., Verté, D. and D-SCOPE Consortium (2018). Exploring the cost of 'ageing in place': expenditures of community-dwelling older adults in Belgium. *Ageing International*. https://doi.org/10.1007/s12126-018-9341-y.

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Britt Mondelaers: assistance with qualitative analysis for a master thesis

Liesbeth De Donder: feedback on research design, analysis and feedback on the complete manuscript

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Dominique Verté: feedback on research design, analysis and feedback on the complete manuscript

Manuscript: Fret, B., Smetcoren, A-S., De Donder, L., Verté, D. and D-SCOPE Consortium (2018). Preventive home visits among frail community-dwelling older adults. The added value of follow-up telephone calls.

Bram Fret: primary author and researcher, coordinating and conducting analysis, reading and writing literature, writing introduction, data and methods, results and discussion, conclusion

An-Sofie Smetcoren: feedback on research design, analysis and feedback on the complete manuscript

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List of abbreviations

ADL = Activities of Daily Living

CFAI = Comprehensive Frailty Assessment Instrument

EU-SILC = European Union Statistics on Income and Living Conditions

IGO = Income Guarantee for Older People

LCA = Latent Class Analysis

OECD = Organisation for Economic Co-operation and Development

RCT = Randomised Controlled Trial

WHO = World Health Organisation