SILVER EMPOWERMENT

FAMILY CARE FOR COMMUNITY-DWELLING OLDER SENIORS IN TIMES OF CORONA: THE POWER OF GIVING AND/OR A BURDEN OF CARE?

dr. Jasper De Witte
Prof. dr. Tine Van Regenmortel

be.Source
A SOURCE OF SOLIDARITY

KU LEUVEN HIVA
RESEARCH INSTITUTE FOR
WORK AND SOCIETY

KU LEUVEN HIVA

RESEARCH INSTITUTE FOR
WORK AND SOCIETY

SILVER EMPOWERMENT

Family care for community-dwelling older seniors in times of corona: the power of giving and/or a burden of care?

dr. Jasper De Witte & Prof. dr. Tine Van Regenmortel

Project management: Prof. dr. Tine Van Regenmortel

Research commissioned by the private foundation be.Source
Chair 'Empowerment of Underprivileged Elderly'

Abstract

Informal caregivers play a crucial role for community-dwelling (older) seniors who are increasingly confronted with care needs on various domains. Indeed, they help them coordinate the formal care, solve practical issues such as meals, transportation and administration, and they simply hold them company. In doing so, they ensure that many seniors can remain living in their own home. However, the downside is that many family caregivers are confronted with 'a burden of care', which can manifest itself on the social, psychological, physical, emotional and/or financial domain. In this respect, we presume that the restrictive measures taken to deal with the COVID-19 pandemic and through which physical contacts decreased, not only have a strong impact on the life of seniors, but also on that of their family caregivers. Based on interviews with community-dwelling seniors (of 80 years and older) and family caregivers, we discuss the needs of both actors, and relate this to this specific context. First, we observe that older seniors often deal with feelings of loneliness, and limited social contacts and activities due to health limitations, structural barriers, a lack of social skills, emotional difficulties creating new bonds and living in a remote neighbourhood. Second, with respect to family care, seniors indicate that although they are in general very satisfied, some of them do have trouble asking their close ones for support. Family caregivers of seniors with high care needs are confronted with a burden of care, which results from the pressure of constantly having to be available, seeing close ones deteriorate, feelings of guilt, a lack of flexibility and demonstrated appreciation from the seniors, and for partners also social isolation and feelings of loneliness. Third, the impact of the measures taken to deal with the Corona pandemic depends on the specific situation. For some seniors (e.g. who live alone, are socially isolated) this led to less physical contacts and more feelings of loneliness, for others (who lived in couple, who were in a high state of dementia) this only had a limited impact on the quality of their lives. For family caregivers of seniors with high care needs the burden of care increased significantly because they took over various tasks that before were done by professionals and other family caregivers, and because many forms of respite care were no longer available. Based on this research, we formulate several policy recommendations that aim to enhance the quality of life of seniors and/or family caregivers, such as ensuring the presence of a family care coordinator who detects and solves the problems of both seniors and family caregivers.

Published by
KU Leuven
HIVA - RESEARCH INSTITUTE FOR WORK AND SOCIETY
Parkstraat 47 box 5300, 3000 LEUVEN, Belgium
hiva@kuleuven.be
http://hiva.kuleuven.be

Contents

Executive summary

Various evolutions result in an increasing demand for informal (and formal) care. Indeed, the ageing of our Belgian population leads to more older seniors (both in absolute and relative terms): while at the moment there are about 330,000 seniors of 85 years or older in Belgium, this will rise to 830,000 in 2070. This increase affects the demand for informal care because of the multicomorbidity that characterises this ageing population. In addition, due to several social and policy evolutions such as 'ageing in place' and the wish of seniors to remain living in their own home, a big proportion of those older seniors will receive care in their own home environment, some with very limited care needs but others with very high care needs.

This implies that the crucial role of family care for community-dwelling (older) seniors will continue to persevere. Family care can be defined as:

> *'The care people give to housemates, family members, friends, acquaintances and neighbours in need of care, not in the context of professional work or a voluntary organisation. [...] Family care is seen as giving help to a family member or a familiar person with a care need as a result of an illness, limitation or old age.'* (Bronselaer, Demeyer, Vandezande & Boer, 2018, p. 13).

Family caregivers help seniors with various tasks such as coordinating the formal care, solving various practical issues such as meals, transportation and administration, and holding them company. That way, they help ensure that many seniors can remain living in their own home. At the moment, the yearly economic value of family care in Belgium is estimated to be about 22.3 billion euros (Desmedt, Bergs, Vertriest, Hellings, Petrovic, & Vandijck, 2016).

Nevertheless, it is also important to acknowledge the limits of informal care, for both seniors and family caregivers. First, not all seniors can appeal to the same extent to informal care, through which professional care becomes even more important for some of them. Second, many family caregivers are burdened by the care they provide, which can manifest itself on the social, psychological, physical, emotional and financial domain. This burden can have a negative effect on the quality of life of family caregivers (e.g. physical or emotional exhaustion, health problems, feelings of loneliness) and seniors (e.g. maltreatment). As a result, it is not only important to take into account the needs of seniors but also those of family caregivers in order to decrease their burden of care, which will have a positive effect on the quality of life of both seniors and family caregivers.

With respect to the COVID-19 crisis, we presume that the restrictive measures taken by the Belgian governments to push back this virus by limiting the physical contact between citizens, significantly affects the quality of life of many older seniors with care needs. Indeed, one of the side effects of these measures is that the social lives of community-dwelling seniors changed drastically. In this respect, there are many indications that social isolation and feelings of loneliness are on the rise because many informal contacts temporarily decreased or fell away. Moreover, in some instances the formal support also decreased or fell away, due to reasons that lay within the service providers or because the seniors themselves were afraid to be contaminated. Nevertheless, the result is the same: formal support was not realised to the same extent nor in the same manner in that period. Further, these measures presumably also affect the lives of family caregivers. Indeed, since professional support in some instances temporarily fell away or decreased, we can presume that many family caregivers took on more responsibilities through which their burden of care (further) increased.

Based on interviews with community-dwelling seniors (of 80 years and older) and their family caregivers, we investigate in this research report how the measures taken to deal with the COVID-19 pandemic affect the life and care situation of both older seniors with care needs and their family caregivers.

We find that seniors are increasingly confronted with difficulties on various life domains, which strongly affect their quality of life. Indeed, seniors are often confronted with the death of their partner, friends and family, and they have more and more physical and mental health limitations, which hinder them from doing all kinds of social activities, sustaining social relations and organising their own care. As a result, their dependency of other people increases. Further, while the life world of older seniors increasingly involves around the own home and neighbourhood, many of them do not live in a 'caring neighbourhood', where there are many services and shops in proximity and where it is easier to sustain a social network. This is problematic because our interviews show that social relations and activities form 'the key for a happy life'. As a result, it is important to stimulate seniors to participate socially and to sustain their social network. In this respect, we observe that many structural barriers impede seniors from participating to society and sustaining a social network: difficulties going out because sidewalks are not adapted, difficulties taking public transportation and a lack of affordable individual transportation. Besides certain personality traits that hinder them from sustaining a social network, seniors also sometimes have emotional difficulties to create new social relations because they feel that they should no longer have fun after the death of their partner or when their partner has serious health issues. For those seniors, psychological support (individual or through group meetings) may help them reflect on these topics, which could positively affect their wellbeing. Next, seniors who do not live in a 'caring neighbourhood' might benefit from 'moving in time' to an adapted residence in such a caring neighbourhood.

With respect to informal and formal care, we find that this is a process that slowly comes together and where both seniors and family caregivers 'roll into'. Seniors in general coordinate and organise the care themselves, but with increasing vulnerabilities family caregivers gradually take over various tasks such as their administration and finances, the organisation and coordination of care, and they often also become 'the person of reference' seniors can appeal on when they have (small or big) practical needs. In this respect, the seniors explain that it is extremely important for them to have at least one person on who they can count at any time. And while some seniors have no problems asking their close ones for support, others find this quite difficult and try look for an equilibrium and try not to ask too much of their family caregivers. With respect to professional care, the seniors find it very important to have a good bond with the professionals since they appreciate their conversations and general company very much. Therefore, they often organise the care so that they regularly see those professionals and they prefer that it remain the same professionals over the years with who they have 'a click'. Further, for seniors with high care needs (e.g. with dementia or Parkinson) it is all the more important that the same professional passes by over the years, and that those professionals are sufficiently formed to deal with difficult situations (e.g. seniors with aggression due to their dementia). Moreover, for seniors with high care needs, we observe that it is important that there is sufficient communication between both professionals and family caregivers in order to notify each other of possible problems. Hereby, it seems to be easier to share information when professionals (and volunteers) belong to the same organisation, and when there is a specific family care coordinator whose task is to detect problems in family care situations and to subsequently offer solutions.

When we assess the perspective of the family caregivers, we see that although they find it evident to provide that care and that it is often very satisfying (~ power of giving), some of them are nevertheless confronted with a severe 'burden of care', which results from a constant pressure to always be available, emotional difficulties when seeing a senior deteriorate, and feelings of guilt when weighing the pros and cons of sending a senior to a residential facility for elderly people. Further, senior family caregivers of their partner with care needs are sometimes confronted with social isolation because they think that it would not be justified to go out and have fun without their close ones. In addition, although most seniors say that they appreciate the support from their family caregivers very much, many of the latter find that the seniors seldom show gratitude or appreciation. This is problematic because the demonstration of appreciation is very important for family caregivers as a form of recognition for all the support they provide, and because it makes the care process more pleasant. Based on the interviews, we detect various ways to lower the burden of care of family caregivers. First, the presence of a ‘family care coordinator’, a reference person family caregivers can talk to about all kinds of practical, ethical and emotional questions would be very positive. Indeed, those coordinators can offer a neutral perspective on their situation and help them make decisions. In addition, stimulating family caregivers to participate to group meetings with other family caregivers would be beneficial because it gives them emotional and practical support. Next, family caregivers of seniors with high care needs benefit from multidisciplinary discussions, in which all involved actors discuss the care situation in order to organise the care around the specific needs of both the senior and the family caregivers. Last, formations and groups discussions could help seniors and their family caregivers to better understand each other’s perspectives on the care situation. This is important because various seniors have sometimes trouble asking for support from their family caregivers, but are at the same time also sometimes little flexible and not always show their gratitude. Hence, better communication between both actors and perhaps a little bit more flexibility on the part of the senior with respect to the care could result in a better relationship, and a better general (family) care situation.

Concerning the COVID-19 pandemic, we see that the impact of the restrictive measures strongly depends on the specific situation. Indeed, whereas some seniors and family caregivers experienced no negative impact, others did. First, we find that the physical contacts of all seniors significantly decreased because they restricted their own social contacts or because certain professionals no longer came and day centres were closed. Further, the social contacts also changed: they became less frequent, less long, and people needed to wear a mask and respect the physical distance through which they became less pleasant according to some respondents. As a result, many seniors indicated feeling lonelier during this period. Nevertheless, for certain seniors (e.g. who lived in couple or seniors in a high state of dementia) these decreased physical contacts did not have a particularly negative effect, and some seniors saw other types of contact (mainly through ICT) increase in intensity. With respect to the family caregivers, we see that the burden of care significantly increased for family caregivers of seniors with high care needs. This was mostly the case when they took over tasks that before were done by professionals or family caregivers that live further away, and when they were no longer able to appeal to sitters or day centres through which they had not a single moment to rest.

Based on this research, we formulate following policy recommendations:

1. increase the mobility of seniors by taking away structural barriers;
2. stimulate ‘moving in time’;
3. give professionals sufficient time to simply talk with seniors and detect needs;
4. ‘triple one’: each senior should have at least one contact, once a week;
5. enhance access to technological communication for seniors;
6. create a family care coordinator in all regions;
7. provide sufficient psychological support, and group discussions with other family caregivers;
8. invest in ameliorating the relationship between senior and family caregivers;
9. COVID-19: invest in social relations, contact, group discussions, and keep day centres open.

Introduction

In our previous research report of the be.Source Chair 'Empowerment of Underprivileged Elderly' (De Witte & Van Regenmortel, 2020), we found that while about 17% of the seniors who did not help a household member with personal care and practical chores feels lonely in 2015, this amounts to 29% among seniors who did help a household member. This ascertainment was yet another indication that (older) persons who provide family care are regularly confronted with 'a burden of care'. Moreover, this also formed the reason to investigate family care of community-dwelling older seniors (of 80 years and older) in more detail in this research report, and relate this to the restrictive measures taken by governments to deal with the COVID-19 pandemic.

This subject is extremely relevant because various social evolutions result in an increased demand for informal (and formal) care. First, we find that the phenomenon of ageing leads to a higher number of (older) seniors, often with care needs on various life domains: while at the moment there are about 330,000 seniors of 85 years or older in Belgium, this will rise to 830,000 in 2070. Second, the demand for informal care also increases in the background of social and policy evolutions such as 'ageing in place' and the wish of seniors to remain living in their own home. Therefore, family care of which the yearly economic value is already estimated to be about 22.3 billion euros in Belgium (Desmedt *et al.*, 2016), will continue to increase.

However, in this respect it is crucial to recognise the limits of informal care, for both seniors and family caregivers. Indeed, it is important to bear in mind that not all seniors can appeal in the same extent to informal care, through which professional care becomes even more important for some of them. With respect to family caregivers, we find that they are often confronted with a (social, psychological, physical, emotional and/or financial) burden of care, which can have a negative effect on the quality of life of both family caregivers (e.g. social isolation, feelings of loneliness, exhaustion) and seniors (e.g. maltreatment). Therefore, it is not only essential to take the specific needs of (older) community-dwelling seniors into account, but also those of family caregivers. Indeed, by taking the needs of the latter into account, the burden of care can lower which will have a positive effect on the quality of life of both family caregivers and seniors.

Further, we presume that the restrictive measures taken by the Belgian governments to deal with the Corona virus have a significant impact on the lives of both older seniors and their family caregivers, and family care in general. Indeed, physical contacts were limited through which some formal support presumably decreased, which might have led to (a) less support for the seniors or (b) family caregivers taking on more responsibilities through which their burden of care further increased. Moreover, in some instances the physical contacts between seniors and their family caregivers might have decreased, which might have led to increased feelings of loneliness and social isolation (among both seniors and family caregivers). Therefore, in this research report, we investigate how the measures taken to deal with the COVID-19 pandemic affect the life and care situation of community-dwelling older seniors with care needs and their family caregivers.

1 | Informal care for community-dwelling seniors

1.1 An ageing population

1.1.1 From a population pyramid to a population rectangle

In our previous research report (De Witte & Van Regenmortel, 2020), we discussed one of the most important realisations of our time in Belgium and many other European countries, namely our ageing population. In this respect, we see that the proportion of seniors and 'older' seniors on the total active population (between 15 and 64 years) is increasing in Belgium. We also observe an increase in absolute numbers in Belgium, from 2.2 million seniors of 65 years or older and 330,000 seniors of 85 years or older in 2020 to 3.3 million seniors of 65 years or older and 830,000 seniors of 85 years or older in 2070 (De Witte & Van Regenmortel, 2020). In Europe, about 30% of the total population will be 65 years or older in 2060, and about 12% will be 80 years or older (Niedzwiedz, Richardson, Tunstall, Shortt, Mitchell, & Pearce, 2016).

The two main reasons for the ageing of our population are the increasing life expectancy and the low fertility (Börsch-Supan, Brandt, Hunkler, Kneip, Korbmacher, Malter, Schaan, Stuck, & Zuber, 2013). Indeed, the success of our welfare state and various medical, technological and scientific advancements have led to better living conditions, food and hygiene, and less hunger and epidemics, which in turn resulted in an enormous decline in child mortality rates.

> *'The progress of our life expectancy is the result of a social process, not a genetic one. It is the result of progress in science and technology, but much more of progress in wealth and wellbeing that are distributed as broad as possible among all members of society.'* (Deboosere, 2020, p. 36).

The decline in child mortality rates mostly led to a rising life expectancy, more than the increasing life expectancy of 'older' people. Indeed, while our population *on average* becomes older than before, people individually do not become much older than before. Or differently, we do not get much older than before, but we do get older with more people. Further possible progress to reduce child mortality is very limited, through which the increase in life expectancy in the Western world is rapidly slowing down. Moreover, our reproduction number has also strongly declined through which there will presumably come an end to the population explosion in our part of the world.

But what does this ageing of the population mean? In short, this demographical shift implies that seniors will *structurally* form a bigger part of our population, in comparison to before. Indeed, our contemporary and future population will count a bigger proportion of adults and seniors, and less children. This is demonstrated by the changing form of our population pyramid (i.e. *'a simple graph that conveys the complex social narrative of a population through its shape'*) (Boucher, 2016). Demographers use such pyramids to gain more understanding in the types of services specific nations or populations need such as schools, hospitals and residential facilities for elderly people. In this respect, the 'traditional' population pyramid has the shape of a pyramid (with a broad base and narrow top), which implies an expanding population which is young and growing. Today, these pyramids are represented mostly by developing countries with high fertility rates and lower than average life expectancies. However, in Belgium this form is shifting towards a shape with a rather broad basis, which remains more or less stable to a high age, and then a small pyramid on top of it. This demographical change towards an older population is represented by countries with considerable social and economic development, and with broad access to quality education and health care (Boucher, 2016). It is important to bear this structural population change in mind in order to correctly assess the need to recalibrate the care system for our seniors because this implies that the latter will structurally form a bigger part of our total Belgian population.

1.1.2 The Belgian 'older' senior population in numbers

On the first of January 2020, exactly 656,787 Belgian citizens were 80 years or older, of which 412,559 women (63%) and 244,228 men (37%). This is about 5.7% of the total Belgian population (https://statbel.fgov.be/nl/themas/bevolking/structuur-van-de-bevolking, 5 June 2020). Further, we see that in 2016 about 8.5% of the Belgian population of 65 years or older lives in an institution for elderly, and that about 5.1% of the Belgian population of 65 years or older receives nursing care at home. We also observe that the absolute number of community-dwelling seniors of 80 years or older will increase the coming 10 years with 20% (Vlaamse Ouderenraad, 2019a). Not only will the number of seniors of 80 years and older increase significantly from 2030 (because of the baby boom generation), but seniors will also be less often admitted to residential settings (Desmedt *et al.*, 2016). Indeed, many of those community-dwelling seniors will receive care in their own home environment, some with very limited care needs but others with very high care needs. In Belgium there are for example about 40,000 people with Alzheimer who still live in their own home (Cès, Flusin, Schmitz, Lambert, Pauwen, & Macq, 2016), and who often have very high care needs. Because of this increase of community-dwelling seniors of 80 years and older, the demand for informal care will also further increase because of the multicomorbidity that characterises this ageing population. As a result, this growing number of community-dwelling older seniors emphasises the importance to reassess the place of these seniors in society, and the care system more specifically.

1.2 Aligning society with the needs of seniors

1.2.1 Ageing in place in a 'caring neighbourhood'

Since seniors structurally form a bigger part of our total population, it is time to reassess the care for seniors and their place in society as a whole. Not only are there more seniors than before, but their defining characteristics are also changing. While there is a general increase in the healthy life expectancy in Belgium, seniors are more often confronted with chronic health problems (Deboosere, 2020), comorbidity and various psychological, physical and functional problems (De Witte & Van Regenmortel, 2019a), through which their general care needs increase. Indeed, 70% of the 136,000 persons with dementia in Flanders live for example at home (Steyaert, 2020). Therefore, it seems appropriate to study how various services and society as a whole can better play into the needs of community-dwelling seniors, and enhance their physical, social and mental wellbeing.

In this respect, the Flemish Council of seniors ('*Vlaamse Ouderenraad*') emphasises the importance of taking the quality of life of seniors in the own neighbourhood as a central point of departure (Vlaamse Ouderenraad, 2019a), and thus of 'ageing in place'. The World Health Organization Center for Health Development defines 'Ageing in place' as

> *'Meeting the desire and ability of people, through the provision of appropriate services and assistance, to remain living relatively independently in the community in his or her current home or an appropriate level of housing. Ageing in place is designed to prevent or delay more traumatic moves to a dependent facility, such as a nursing home.'*
> (World Health Organization Center for Health Development, 2004, p. 109).

‘Ageing in place’ is a suitable policy goal because the overwhelming majority of seniors want to stay at home and in their own community as long as possible (Vlaamse Ouderenraad, 2016). Indeed, Flemish seniors who become dependent on care want to remain in their own home as long as possible (79%), followed by a service flat (43%), ‘adapted’ living (32%), a nursing home (9%) and only then would they want to move in with their children (4%) (Studiedienst Socialistische Mutualiteiten, 2016). Many seniors do not want to live in with their children because they do not want to burden them too much (Studiedienst Socialistische Mutualiteiten, 2016). Besides the fact that the majority of seniors want to stay at home as long as possible, ‘ageing in place’ is also a suitable policy goal because ‘proximity’ becomes more important when people get older (Vlaamse Ouderenraad, 2019a). According to this ubiquitous policy concept, people should be able to age in their own residence or in an adapted residence in their neighbourhood, while the residential facilities for elderly people are only for those that need intensive care. This implies that ‘ageing in place’ requires a holistic and transversal approach that takes into account all life domains within the local neighbourhood, such as social and cultural participation, mobility, housing, wellbeing and health (Vlaamse Ouderenraad, 2019d). Such a focus on integrated care within the local neighbourhood is in line with various policy initiatives in Flanders, such as ‘neighbourhood-oriented care’ and ‘caring neighbourhoods’. The first refers to strengthening local networks of local authorities, professionals and citizens to better respond to various needs with reference to wellbeing, social needs and living. The second, ‘caring neighbourhoods’, refers to neighbourhoods in which people of all ages can live and where participation (of young and old) is stimulated (De Decker, 2020). From the literature, we can discern a number of important characteristics that define such neighbourhoods.

First, in ‘caring neighbourhoods’ the offered care should be adjusted to the various needs of a diverse senior population. In this respect, it is important to provide a diverse offer in the local neighbourhood with respect to housing, by offering sufficient possibilities for home care, day centres, night care and short stay (Vlaamse Ouderenraad, 2018a). Further, formal and informal care should be complementary to each other. Hereby, it is important to respect the wishes of the seniors: research shows that seniors count first on their partner with respect to the care they receive, followed by professional home care, and only then limitedly on their children. Furthermore, the tasks and intensity of the offered care also differs according to the specific care provider: children for example mainly offer support with mobility/transportation, company, administration and the household (Studiedienst Socialistische Mutualiteiten, 2016), and friends and neighbours in general do not give intensive and frequent support (De Decker, 2020). Therefore, it is also important to recognise the limits of informal care, because its possibilities strongly depend on the characteristics of the specific environment such as the work situation, geographical distance, education level, wellbeing and characteristics of the neighbourhood (Bronselaer *et al.*, 2018). Moreover, many family caregivers become old themselves since demographic evolutions will result in less family caregivers below the age of 65 years old and more of 65 years or older (Cès *et al.*, 2016). Hence, it is important to provide sufficient basic community care services in proximity, where qualitative professional care and support can be offered (De Decker, 2020). In this respect, ‘local service centres’ can play an important role in caring neighbourhoods, for example to alleviate feelings of loneliness among seniors (Vlaamse Ouderenraad, 2019d). They can work together with other local organisations and first line actors, and that way realise early-prevention and detection of vulnerable seniors. Hereby, the Flemish government states that it wants to increase awareness about loneliness and shall invest in ‘caring neighbourhoods’ by providing a neighbourhood-oriented approach for care (Vlaamse Ouderenraad, 2019b). In this respect, we have already demonstrated in our first report that it is important to keep in mind that there is no such thing as *the* seniors and that feelings of loneliness come in multiple forms. As a result, one-size-fits-all measures do not exist and intervention strategies should be tailored around the specific situation of the senior (De Witte & Van Regenmortel, 2019a). Next, caring neighbourhoods should also give sufficient attention to mental health problems of seniors. Although some research finds that seniors of 60 years or older are happier than younger generations because they are more satisfied with their social relations and health (Vlaamse Ouderenraad, 2019c), older seniors of 75 years and older are found to be more vulnerable when it comes to mental health. However, despite their significant psychological vulnerabilities, seniors make less use of psychological support than younger generations (Vlaamse Ouderenraad, 2020a). The Flemish Council for seniors states that the mental health care sector for seniors is lacking in general, and that seniors remain structurally excluded from this offer, despite the gravity of their situation (Vlaamse Ouderenraad, 2019b). Only after protest from the social and health sector in 2019 did the federal Belgian government agree to reimburse a limited number of psychological sessions for seniors (Vlaamse Ouderenraad, 2018a). Nevertheless, from our first research report (De Witte & Van Regenmortel, 2019a) we find that self-help and talking groups prove to be fruitful, but certainly also professional care such as for example the senior team 'Elder' of the Centre of Mental Health in Brussels. Based on the empowerment framework, this specialised team offers formations and narrative care for seniors, which aim to strengthen them and reinforce their resilience (Vlaamse Ouderenraad, 2019b).

Another defining characteristic of 'caring neighbourhoods' is that they aim to stimulate participation and social inclusion by investing in sufficient green space, rest points, public sanitation, and foremost (intergenerational) meeting places through community initiatives like neighbourhood shops and cafeterias. That way, they try to compensate for the disappearance of numerous local services, which is important because seniors (who in general participate less than younger people) are often the first victim when local services disappear (Vlaamse Ouderenraad, 2019b). Those meeting places not only stimulate social cohesion and allow to sustain a stable social network (De Decker, 2020), but they can also indirectly alleviate feelings of loneliness (Vlaamse Ouderenraad, 2019b). The Minister of wellbeing in Flanders emphasises the importance of intergenerational contact in the fight against loneliness among seniors (Beke 2019, p. 27). This is in line with other research, which states that it is important to invest in age-divers networks when people are younger, in order to prevent social isolation in later life. In this respect, local institutions can create the key requisitions for intergenerational contact through which people from different ages are physically brought together in one place. Those encounters ideally require equality between the participants, a common project (e.g. not like in residential facilities for elderly people, where seniors are often only on the receiving end), and inclusiveness by being accessible to various age groups (Yates, 2015). Further, policy makers could also for example support more participation through projects that create a link between wellbeing and culture (Vlaamse Ouderenraad, 2019d), such as the project 'Long Live Arts'. Such projects not only aim to create more connections between people, but also help seniors to deploy themselves and strengthen their wellbeing. Further, caring neighbourhoods can also stimulate participation indirectly by providing sufficient basic community services in proximity such as enough means of transportation (Vlaamse Ouderenraad, 2019b). Indeed, it is important to guarantee the availability, affordability and accessibility of transportation because the observed decrease of public transportation (busses, free busses, busses people can ring) in Flanders is said to form a barrier for seniors to participate (Vlaamse Ouderenraad, 2019d). Last, stimulating the participation of seniors through volunteering also has many positive benefits for both seniors and society as a whole. Indeed, it reinforced their social network, gives them a good feeling and more self-esteem, and it strengthens their resilience (De Witte & Van Regenmortel, 2019b).

1.2.2 Moving in time

Although most seniors prefer to stay in their own home and neighbourhood, it is important to realise that for many seniors neither their home nor neighbourhood fulfils the above-described characteristics of 'a caring neighbourhood'. Various academics emphasise that this the idea of 'ageing in place' in caring neighbourhoods which is ubiquitous in elderly research and policy, is not realised at the moment. Therefore, it is important that people (together with family caregivers) already think in advance about their 'old day' and take precautionary measures. In this respect, research shows that only 8% of the seniors makes arrangements for the care later on (Studiedienst Socialistische Mutualiteiten, 2016). However, given the fact that the idea of 'caring neighbourhoods' is not realised for many seniors, it should be made easier to move to an adapted residence and living environment that enable social contacts, provide easy access to both formal and informal care, have sufficient local shops and means of transportation. Indeed, such an environment, which in practice often refers to village centres and cities, will have a positive effect on the quality of life of seniors. Although research shows that a bigger proportion of seniors (in comparison with younger people) want to live in a compact residence in village centres or cities, the majority still chooses not to do so. The latter can be explained by seniors becoming less willing to move due to physical limitations, the emotional bond with the residence in which they live, the existing social contacts in their actual neighbourhood, practical and administrative difficulties of moving, and a lack of sufficient qualitative and affordable adapted residences (Vlaamse Ouderenraad, 2019a).

1.2.3 Residential facilities for elderly people

In line with the previous, it is equally important that the quality of life of residents of residential facilities for elderly people is assured. In this respect, it is important that seniors receive sufficient support when they move from their own home environment to such a facility (Vlaamse Ouderenraad, 2020a). Further, according to some researchers (Vermeerbergen & Van Hootegem, 2020) it is also preferable that residential facilities for elderly people are decentralised (e.g. through small-scale units in big-scale structures) and geographically placed in the heart of cities and villages (instead of outside of cities and villages). This allows residents to participate and interact more easily with their environment through the organisation of cultural activities (e.g. visiting museums, doing art trajectories), opening up spaces of the facility for neighbourhood activities, stimulating intergenerational contact (e.g. through projects with schools, the day-care centre for children), and it would increase informal support possibilities (Vlaamse Ouderenraad, 2018a). Moreover, that way, residential facilities for elderly people could also more easily make a link between culture and wellbeing, which enhances the participation of seniors (Vlaamse Ouderenraad, 2019d). It further seems appropriate to increase the personnel norm of those Flemish facilities to the increased dependency of their (older) residents (to alleviate the high stress levels of staff). Further, the composition of the personnel would also benefit from a shift from a mainly medical to a more holistic profile of the staff, whereby for example family caregivers and professionals that focus on general wellbeing (e.g. psychologists, animators) are given a more prominent role (Vlaamse Ouderenraad, 2018b).

1.3 Informal care and family care for community-dwelling seniors

One of the aspects that makes it possible for community-dwelling seniors with care needs to keep living in their own home is the presence of informal care. Numerous Belgian seniors would no longer be able to live in their own home without the crucial support of informal caregivers. Not surprisingly, informal care has an important social and economic role, and increasingly becomes the starting point of care (Cès *et al.*, 2016). Family caregivers not only support vulnerable seniors with their care needs, but they often also stimulate them to remain active and participate to society, increase their autonomy, self-dependency and empowerment (Vlaamse Ouderenraad, 2016), for example by simply accompanying them to the grocery which can be seen as 'a day out' (Cès *et al.*, 2016). As a result, their role cannot be underestimated for the quality of life of seniors with care needs.

1.3.1 The hazard of the socialisation of care

The ‘support model’ of people in need of the World Health Organization (WHO) refers to five concentric circles of care and support, which form a continuum from informal to formal care:

1. the individual and self-care;
2. family care at home;
3. volunteers and services in the neighbourhood;
4. general professional care and support;
5. specialised care and support (Bronselaer *et al.*, 2018).

This model in which subsidiarity is a central principle, aligns closely to one of the most important policy developments with respect to wellbeing and care in Belgium, namely the ‘socialisation’ of care. The latter refers to:

> *‘A shift in care whereby we strive to give people with limitations, with chronical illnesses, vulnerable seniors, youngsters with behavioural and emotional problems, people in poverty, ... with all their possibilities and limitations a meaningful place in society, support them where necessary and organising care as much as possible in an integrated manner in society. Concepts that play a role in this respect are de-institutionalisation, community care, empowerment, strength- and context oriented, demand-driven and respite care.’* (Department Welzijn, 2013, p. 3).

This concept seems to align perfectly with the above-described idea of ‘caring neighbourhoods’, whereby all formal and informal actors in a neighbourhood work together to give seniors (and others) the care and support they need.

However, it is important to realise that this policy development - like the ‘support model’ of the WHO - withholds the danger to individualise care if it refers to a continuum whereby people must first make use of all their informal care possibilities before being allowed to make use of formal care. In this respect, Flemish policy documents clearly state that the control of care lays as much as possible within the patient or family caregivers themselves, and that as a working principle professional services, care networks and associations must as much as possible appeal to the ability and strength of the user and his family caregiver, taking into account their carrying capacity. The Flemish government emphasise to prioritise the least drastic form of care, namely self-care, family care and professional home care if possible (Vermeulen & Declercq, 2011).

However, when informal care receives a more prominent role, the inequalities with respect to informal care possibilities will also become more present. Indeed, all people cannot appeal in the same extent to informal care, which depends on various factors such as their socioeconomic position, their general social capital, the presence of reciprocity in relationships, confidence in others, social skills, ... People who live in poverty for example not only have less bonding and bridging social capital themselves, but their social network also often has less capital through which they can offer less support. Moreover, giving support is often a precondition for asking others for help because of the importance of reciprocity in a relationship and feelings of shame. *‘The Brussels story of the power of informal networks to care is rather a story of income, ability to cope, skills and accessibility of social services, than a story about age, gender, migration background or residence permit.’* (Thys & Vermeulen, 2018, p. 9).

From this follows that vulnerable groups such as people who live in poverty, older seniors, people with a migration background and socially isolated people have less possibilities to appeal to an informal care network, through which professional care becomes even more crucial for them. Indeed, professional support can have a positive effect on the informal contacts people have (e.g. by helping them realising more reciprocity in their relationships). Nevertheless, a social network is not always sufficiently stable to appeal on, and people need sufficient time to construct a stable social network. Appealing to an instable network might be a burden and even endanger that network. Therefore,

> *'The socialisation of care will only be feasible for many people who live in poverty, when they first become stronger financially and when the personal and structural barriers are lowered with the goal of full participation to social life.'* (Thys & Vermeulen, 2018, p. 10).

Indeed, it is important to be aware of the possible negative side effects of this model for vulnerable groups, who have less informal support.

Vulnerable groups should be able to appeal to professional help without any feeling of guilt: informal and formal care should be complementary and should not be placed on a continuum from informal to formal care. Therefore, a pie chart is a better conceptualisation, whereby informal and formal support are equal and whereby the type and amount of informal and formal support depends on the specific needs and possibilities of the individual: *'where self-care and informal care are insufficient, professionals should be active and take initiative.'* (Thys & Vermeulen, 2018, p. 11). In sum, informal care is positive when it strengthens the self-determination and emancipation of the individual, but every person should have the right to make use of formal care when there is no informal network or when they do not want to make use of their informal care (Thys & Vermeulen, 2018). Informal care should be a positive choice of both the senior and the informal caregiver, which is in line with the idea of empowering care (van Regenmortel, 2011).

1.3.2 Informal care and family care defined

Informal care refers to:

> *'All help and support that is not offered in the context of a profession and that is not compensated as professional work. The relation between the person in need of care and the caregiver is characterised by social and/or geographical proximity. The care content is characterised by activities with a 'care'-character with the goal to improve the physical, mental and social wellbeing of the person in need of care, and transcends the usual care that partners or parents and children that live in are supposed to give each other mutually.'* (Bronselaer *et al.*, 2018, p. 12).

In this respect, many different forms of informal care exist such as family care, self-help, buddy care, foster care, community care, voluntary care and neighbourhood care. But although these are distinct forms, they all have a number of characteristics in common. First, informal care is not compensated for financially and is not done professionally. Second, informal care always supposes some degree of social and/or geographical proximity since it is given by family, friends, neighbours or engaged citizens of the same neighbourhood or city. Third, informal care concerns 'care' and not 'cure', and the goal is to enhance the physical, mental and social wellbeing of the care receiver. Last, we distinguish between informal care and usual care that is mutually given by members of the same household. Hence, it refers to other care than usual care (Bronselaer *et al.*, 2018).

Family care is a specific form of informal care, and can be defined as:

> *'The care people give not in the context of professional work or of a voluntary organisation, to housemates, family members, friends, acquaintances and neighbours in need of care. [...] Family care is seen as giving help to a family member or a familiar person with a care need as a result of an illness, limitation or old age.'* (Bronselaer *et al.*, 2018, p. 13).

A family caregiver is *'the natural person who helps and supports one or more persons with limited ability to self-care in daily life because of a social and emotional bond, not professionally but more than occasionally.'* (Bronselaer *et al.*, 2018, p. 13).

It is important to realise that just like there is no such thing as 'the' senior, there is no such thing as 'the' family caregiver. Indeed, family caregivers differ according to gender, age, socioeconomic status, the type of relation with the person in need (e.g. children, partner) and if they live in the same household or not (Bronselaer *et al.*, 2018). But although those distinct types of family care often require specific support services (Vlaamse Ouderenraad, 2016), they have several characteristics in common. First, family caregivers are characterised by an emotional connection through which the character of the care is less voluntary and they not seldom feel obligated to care. This social and emotional bond is an important distinction in comparison with other forms of informal care (e.g. care by volunteers), just like the durability of the care and the fact that family caregivers do not offer care through an organised network. Because of this emotional connection, many family caregivers do not consider them to be a family caregiver, and they find it morally and politically obvious to provide that care. In this respect, the engagement of family caregivers is driven by various motivations. First, the parental or marital bond results in reciprocity (and intergenerational solidarity), through which this engagement becomes self-evident and does not have to be accounted for. Second, the specific place in the family states which child will take care of the parent, which is also affected by geographical and emotional proximity. Third, there is said to be a moral duty as a reason for solidarity, which is explained by striving for humanistic and society values and by a negative idea of residential facilities for elderly people. Four, the offered support creates a bond between both actors and redefines their relationship in a new, better direction (Cès *et al.*, 2016). In this respect, we see that family caregivers are very motivated and involved, through which they push their limits to fulfil the own and the needs of the seniors (De Koker, 2018). A second characteristic of family care is that the intensity and frequency of family care is relatively high: it is given on a higher than occasional basis (at least once a week is the criterion). However, this does not mean that family care is per definition given on a constant basis: its intensity can vary greatly. Next, we observe that while volunteering has numerous benefits such as wellbeing and enriching the own identity, family caregivers are more often negatively affected by depression or the burden of care. In this respect, the concept of 'durable family care' is useful: it is measured by the quality of life of the family caregiver and by the possibility to continue to give care. This durability of family care is determined by the motivations for care, the type and intensity of the care situation (and its impact on education, work, family, free time, health, ...), the available resources (e.g. coping styles, resilience, experiencing appreciation or support), the extent to which multiple actors share the care for the same person, and the subjective experience of the care situation (Bronselaer *et al.*, 2018).

1.3.3 Informal care in numbers

Although the current policy context increasingly emphasises the importance of informal care, there are indications that the availability of informal care decreases over all ages and both sexes. A study of the Flemish government shows a decrease of the informal care given to a sick, handicapped or 'older' family member, friend, acquaintance or neighbour in the period 2011-2014 from 38% to 26% of all Flemish citizens of 18 years and older (Vanderleyden & Moons, 2015). Indeed, several evolutions will result in a decrease of informal care:

> *'Socioeconomic changes; especially the increase of the number of women on the labour market, the rise of the number of divorces, the increase of the number of single households, and the decrease of the nativity can limit the availability of family care in the future. Based on demographic prognoses it is predicted that the available offer of family care will no longer satisfy the demand. In the long run there will be more seniors with care needs and less caring people of fifty years old.'* (Desmedt *et al.*, 2016, p. 18).

The latter relates to the care index (i.e. the relation between the number of 'very old' and the population between 50-59 years old), which is relevant because this mid-generation offers the most regular informal care for both seniors and children. In this respect we see that this familial care index in Flanders will rise from 0.37 in 2010 (i.e. there were three potential informal caregivers between 50 and 59 years old for each senior of 80 years or older) to 0.59 in 2030, which implies that the potential of informal care will significantly decrease (Vermeulen & Declercq, 2011).

Despite this decrease, many people provide family care: at the moment there are about 600,000 family caregivers in Flanders (Vlaamse Ouderenraad, 2016) and in Wallonia, about 11.4% of the adults of 25 years or older state that they are regular informal caregivers in 2001 (Bourguignon, Degrave, Eggerickx, Ghilain, Leider, Lits, Marquet, Merla, & Sanderson, 2016). Research shows that about 21% of the Flemish citizens of 45-75 years old on average provide family care for about 10 hours a week. Moreover, on average, family caregivers provide care during a period of more than 6 years, and about 22% of them already give care for more than 10 years (Studiedienst Socialistische Mutualiteiten, 2016). Although Belgian family caregivers for seniors with needs find it difficult to estimate how many hours they give care, research shows that they spend on average about 4.2 hours a day providing family care (Cès *et al.*, 2016). So despite its decrease, family care remains extremely important, both socially and economically. Socially, research shows that family care can for example result in a limitation of the duration of hospitalisations (Cès *et al.*, 2016). Economically, family care in Flanders counts for about 121,000 fulltime jobs of an 38 hour week (Studiedienst Socialistische Mutualiteiten, 2016), and family caregivers are said to have a value between 621 and 1,189 euros a month (Cès *et al.*, 2016). In total, the economic value of family care in Belgium and in Flanders amounts to no less than respectively 22,27 billion euros and 11,38 billion euros on a yearly basis (Desmedt *et al.*, 2016).

1.3.4 Different types of family care

1.3.4.1 The classic profile

The classic profile of the family caregiver is that of a low-skilled woman, of 45 to 70 years old, who does not work or only works part-time, and who takes care of her very old parents or partner. In general people between 45 and 70 years old provide more care because their parents are at an age where they need more often care, and they also often provide care for their children and/or grandchildren (Desmedt *et al.*, 2016). Research further shows that the proportion of the population that gives informal care increases with age until the age group of 55-64 years old (37% gives informal care). Of the people of 75 years and older only 16% gives informal care (Vanderleyden & Moons, 2015). Both the Health survey and the Flemish survey of Socio-Cultural Change find similar results: informal caregivers are more present in the groups of 25-64 years old, and there are very little adolescents or young adults who provide family care (Bronselaer *et al.*, 2018).

With respect to the care they provide, research shows that family caregivers offer various types of support: company, help with mobility and transportation, administration, finances and the household (Studiedienst Socialistische Mutualiteiten, 2016). In general, the type of support family caregivers provide is complementary to the care that is given by professional home care: while family caregivers perform the ‘lighter’ tasks, professional home care performs the ‘heavier’ tasks such as personal care and work in the household. In this respect, we find that in 60% of the cases in Flanders, family care is supplemented by professional home care (for on average 6 hours a week). Together with the 10 hours a week that family care is offered, this amounts to 16 hours a week of which about 60% is given by the family caregiver and 40% by professional home care (Studiedienst Socialistische Mutualiteiten, 2016).

1.3.4.2 Various types of family care situations

However, since there is no such thing as ‘the’ family caregiver, it is essential to distinguish between various types of family care situations. This is important because the characteristics of the family care situation (e.g. the intensity, type of care, the liberty of choice) depend strongly on the care needs of the senior (e.g. with IADL or ADL), the specific relation (e.g. partner, child) and the geographical proximity (e.g. living together or not) (Cès *et al.*, 2016).

a) The intensity of care

There is an important distinction to be made between family caregivers who live in with a senior with care needs (about 40% in Belgium) and those who do not (about 60%). Indeed, while family caregivers who live in are most often partners (73%) or children (23%), family caregivers who do not live in are in majority children (78%) (Cès *et al.*, 2016). From this follows that family caregivers who live in are much older (68 years on average) than those who do not (55 years on average). We also observe that family caregivers who do not live in more often still work (about 60%) and are more often women, which can be partly explained by the higher sociocultural pressure on women to care (Cès *et al.*, 2016). Further, we find that family caregivers who live in give more intensive care. Indeed, they devote more time to family care than family caregivers who do not live in (respectively between three and ten hours a day, and between one and two hours a day). This is partly explained by the higher dependency level of seniors who live in with their family caregivers, and by the fact that family caregivers who live in with the senior find it more difficult to refuse to give care (Cès *et al.*, 2016). Moreover, according to family caregivers who live in with the senior, living in is essential to be able to sufficiently help them, and about 70 000 seniors would have no other option than to go to a residential facility for elderly people if the family caregivers wouldn't live in with them (Studiedienst Socialistische Mutualiteiten, 2016).

b) The type of care

Besides the intensity of care, also the type of care also differs between family caregivers who live in with a senior and those who do not. While family caregivers who live in provide support with IADL, ADL and general supervision, those who do not live in mostly only provide help with IADL. Indeed, whereas about 46% of the family caregivers who live in provide support with ADL (personal hygiene, incontinence or toilet visits), this is only 18% among family caregivers who do not live in. This can partly be explained by the psychological restraint to help with personal care: whereas children often feel ashamed to provide support with personal hygiene, partners do not. Moreover, this feeling of shame is strongly affected by gender: a son will rarely help his mother with ADL. Nevertheless, daughters also prefer to leave such tasks to professionals.

Further, family caregivers who do not live in with the senior with care needs also help mostly with IADL because that type of care can more easily be planned in accordance with the personal life of the family caregiver (Cès *et al.*, 2016). In this respect, while family caregivers who live in mostly help with laundry, medication giving, the organisation of care and transportation, family caregivers who do not live in mostly help with groceries, followed by financial administration, transportation, organisation of home care, laundry, meals, medication and domestic tasks (Cès *et al.*, 2016).

Last, while family caregivers who do not live in only spend about 0.6 hours a day to supervision, this increases to 7.6 hours a day among family caregivers who do live in with the senior. For the latter, this may result in a feeling of being locked up in their own home (Cès *et al.*, 2016). Therefore it is no surprise that loneliness and social isolation are important risk factors for family caregivers who live in (Cès *et al.*, 2016).

c) The use of complementary formal and informal care

Further, the extent to which people use complementary informal and professional care also depends on the characteristics of the specific family care situation (Studiedienst Socialistische Mutualiteiten, 2016). While family caregivers who do not live in with the senior are more often assisted by other family caregivers, family caregivers who live in are more often alone in the care situation. This is partly explained by the fact that family caregivers who live in are more often the partner and that they do not want to burden their children. Indeed, seniors often try to find a balance and avoid burdening their close ones (Cès *et al.*, 2016).

With respect to complementary professional care, we find that about 75% of the family caregivers makes use of home care and household help, and 20% receives 'meals at home'. In this respect, family caregivers and seniors find it often difficult to let professionals help them, which can partly be explained by difficulties to accept the own vulnerability and loss of autonomy which leads to feelings of shame. Further, this can also be explained by not being satisfied with the quality of services such as staff turnover, the hour on which professionals arrive, organisations taking the life world of the senior insufficiently into account, practical problems or because of not being satisfied with activities in day centres, professionals with too little time and which are not always friendly, and by financial means (Cès *et al.*, 2016). Moreover, family caregivers often do many IADL tasks because they feel that they belong to the public good and must be done anyway. In this respect, research shows that 18% to 31% of the family caregivers of 75 years or older who care for seniors with IADL needs and incontinence do not get any formal support, which is problematic because such support can ease the psychological burden (Cès *et al.*, 2016). With respect to ADL limitations, we find that seniors who live together with their family caregiver use home care less. This presumably results in a higher 'burden of care' for the family caregiver (when they take over these tasks) or in the senior not receiving the needed help. Only 37% of the people who need help with ADL regularly receive a nurse at home. Moreover, about 18% to 22% of the seniors with incontinence, serious ADL limitations and who do not have a family caregiver that lives in with them, do not make use of formal care. Consequently, many of those seniors will receive no help at all because we know that family caregivers who do not live in seldom give ADL support. Moreover, when this support is in fact given, it presumably forms an emotional burden for those family caregivers due to difficulties being confronted with the intimacy of the parents and shame, and for many older family caregivers this support would presumably form a physical burden. Last, we find that only a few people use respite care (e.g. sitters). And while seniors with family caregivers that live in make more often use of day centres (which are in general rarely used), only 5% of the seniors use short stays in residential facilities for elderly people (Cès *et al.*, 2016).

1.3.5 The 'burden of care'

Offering family care has many beneficial effects such as satisfaction, emotional support, feeling proud, acquiring new skills, expressing emotions, intimacy, reciprocity, personal growth and better social relations (Van Audenhove & Declercq, 2007). Nevertheless, although family care is very important and allows many seniors to remain living in their own home, providing family care is not always easy.

> *'Giving family care is mostly experienced positively, but nevertheless the overload on the physical, emotional, financial and social domain cannot be underestimated. Vulnerable family caregivers experience more overload and find the way to professional support less easily.'* (Vlaamse Ouderenraad, 2016, p. 14).

In this respect, it is important to realise that while volunteering is most of the time a positive choice, this is much less the case for family caregivers. As a result, those latter are more often affected by the so-called 'burden of care' (Bronselaer *et al.*, 2018), which can manifest itself on various domains: the social (e.g. social isolation, conflictual relationship), psychological (e.g. more depression, fear, feelings of loneliness), physical (e.g. exhaustion, higher mortality), emotional (e.g. worries) and financial domain. Moreover, in some instances it can lead to maltreatment of the senior (Vlaamse Ouderenraad, 2016). With respect to the latter, we observe that when family caregivers are confronted by a severe burden of care, this can lead to physical maltreatment, psychological maltreatment, neglect, the violation of rights and financial abuse of seniors(Royers, 2010). In this respect, research shows that in Flanders the 'burden of care' increased between 2011-2014: while 18% of the family caregivers felt heavily burdened in 2011, this increased to 23% in 2014 (Vanderleyden & Moons, 2015).

1.3.5.1 Determinants

The experienced burden of care refers to the degree the care is experienced as a burden or problematic by the family caregiver. Based on social stress theories, the care needs of seniors can be seen as a stressful event for family caregivers. In this respect, the *stress-appraisal model* of Yates, Tennstedt & Chang (1999) tries to explain the psychological wellbeing of family caregivers by looking at a number of factors: primary stressors such as the intensity of care (i.e. the degree and extent of the care needs), the perception of the family caregiver to be burdened, and mediating factors such as internal sources (e.g. feeling of mastery, quality of relationship) and external sources (e.g. formal care). Next, other research also mentions the importance of the type of relation between senior and family caregiver (living in or not; child or partner), and other roles of the family caregiver (e.g. work and family). The latter is important because we suppose that human time and energy is not infinite through which taking on multiple roles could lead to a burden and conflicts, which in turn can lead to psychological problems (De Koker, 2018). Last, several organisational factors also seem to determine the burden of care (Scheepmans, Debaillie, De Vliegher, Paquay, & Geys, 2004).

First, with respect to the primary stressors it is clear that the burden is higher when family caregivers offer more intensive care and when they perform a broad range of tasks, for many years. This strengthens the 'wear and tear' hypothesis (De Koker, 2018). The specific characteristics of the support may result in both a psychological and physical burden of care. Hereby, we find that often the care situation is characterised by high levels of insecurity and unpredictability (because the care situation can always change because of changing needs and the high vulnerability of the senior). This insecurity can lead to a psychological burden of care, whereby family caregivers are often worried because they are continuously confronted with new problems, because of doubts about how long they can continue offering support and at what moment it would be best to move the senior to a residential facility for elderly people (Scheepmans *et al.*, 2004). Further, the intensity and range of care tasks can also result in a physical burden of care due to a lack of sleep and rest (e.g. because of helping the senior during the night to go to the restroom) (Scheepmans *et al.*, 2004). This physical burden is very important because the health of family caregivers and their general exhaustion is often one of the most important reasons to stop the family care (Scheepmans *et al.*, 2004).

Second, internal resources can decrease the burden of care. Hereby we look at the personality traits of the family caregivers and the bond between family caregiver and seniors. With respect to the personality, research shows that family caregivers need sufficient flexibility because they need to be able to adapt to ever changing circumstances and demands with respect to the organisation of care. Therefore they also need to be able to go out of the own comfort zone, equilibrium, motivation, insight and talent to organise. In this respect, they also need sufficient insight into the care situation and what can be expected from various actors, and therefore also be sufficiently vocal and able to impose certain wishes to professional home care (Scheepmans *et al.*, 2004). Next, it is important for the burden of care that family caregivers have a good care relation with the senior. Indeed, a good relation can form a buffer against stressing and heavy care situations, through which the family caregiver experiences the care situation more positively (Van Audenhove & Declercq, 2007). In this respect, the burden will be higher when they have a bad relationship, and the burden will be lower when both parties experience a positive relationship through reciprocity, love and friendship (De Koker, 2018). In this respect, research shows that seniors in general experience a warm relation with their family caregivers (Vermeulen & Declercq, 2011). Family caregivers themselves also rate the quality of the relation high, but less high than the seniors (Vermeulen, Declercq, & Spruytte, 2011). About 7% of the family caregivers who live in and 11% of those who do not live in with the senior experience that they have a bad relationship with the senior which is characterised by conflict and little warmth

(Vermeulen & Declercq, 2011). Further, about 20% of the family caregivers is often annoyed by the senior. Hereby, research shows that the relationship is affected by various factors, of which reciprocity is one of the most important ones (Vermeulen *et al.*, 2011).

Third, with respect to the external resources we observe that the presence of professional complementary support is an important factor. On the one hand, professional care is experienced as positive because of the support they offer which gives the family caregivers time to breathe, but also because professional care can reassure family caregivers as a sort of control. Hereby, the knowledge, appreciation and competences of the professionals are important elements (Scheepmans *et al.*, 2004). Nevertheless, some research also shows surprisingly that professional support can lead to a higher burden of care, which can be explained by various factors. Indeed, professionals can show a lack of attention for the family, little involvement, and even blaming family members for certain problems (Van Audenhove & Declercq, 2007). Next, family caregivers not seldom feel an ambivalence with respect to professional care. While on the one hand, professionals help them by lowering their load management and giving more time for themselves, on the other hand, professional support means less autonomy and privacy, other tasks and stress due to organising the care, coordination and monitoring of the quality of care. Further, in this respect, the quality of the relation between the senior and professionals is an important factor that determines the way family caregivers experience the support. Hereby, high personnel turnover makes it more difficult to construct a qualitative relationship, which will increase the burden of care. In line with this, also the relationship between the professionals and family caregivers is important. Hereby, family caregivers find it important to be recognised by the professionals as the coordinators and final responsibles of the care (by monitoring the quality of care and stepping in when professionals cannot come), and also the sharing of information and knowledge is important in this respect. As a result, research shows that the use of professional care is always a consideration of both the positive and negative aspects (De Koker, 2018).

Last, the type of relation between family caregivers and seniors (living in or not, parent or children) also determines the burden of care, just like factors such as age and income. With respect to the type of relation between family caregivers and seniors, we find that women and partners are most burdened, which can be explained by the higher care intensity and emotional closeness (De Koker, 2018). Hereby, family caregivers who live in with the senior (which often refers to the partner) not seldom feel like they are obligated to provide the care. Indeed, they have less 'legitimate excuses' not to offer care, such as other priorities (family or work), not being available (geographical distance) or not being able (because of a lack of skills). Another explanation is that care in the own household is more intensive and has more negative side effects because it is more difficult to protect the limits of the caregiver in the own household. Further, we also see that partners experience more burden than children, which can be explained by more time investment, giving care for a longer period, and taking on a broader range of tasks. In addition, the expectations towards partners are higher, and partners in general receive less support from other family caregivers, professionals and volunteers. And while partners are more often caregivers out of love and friendship, children more often provide care through a sense of duty and more often combine their care role with other roles (e.g. family and work) (De Koker, 2018). *'They [family caregivers who live together with the senior] are especially severely burdened when they take on ADL-care, the responsibility for IADL and psycho-social support for the person with care needs.'* (Koning Boudewijnstichting, 2016, p. 64). Nevertheless, children who do not live in can also be confronted with a high (emotional) burden of care, for example because they are confronted with feelings of shame and with the intimacy of their parents. Further, with respect to the age of family caregivers, we see that the physical burden of family caregivers of 70 years or older increases because they have less physical capacities, more health problems and a higher risk to become socially isolated. Next, we also see that people who live in Belgian municipalities with a lower median income are more often psychologically burdened, which can be explained by them making less use of professional services because they can pay less easily for it, and because they have less access to information and services. Reversely, citizens in richer municipalities have a higher dependency, which can be explained by them living longer and using more professional services (Cès *et al.*, 2016). The same is the case in Flanders: family caregivers with a lower socioeconomic position offer care more intensively, have less access to information through which they appeal less to professional aid, and often have a more difficult work-care combination. And Flemish family caregivers with a relatively good socioeconomic position provide more often moderate intensity of care, through which it seems important to provide sufficient professional care and respite care (Bronselaer, Festraets, Moons, Vandezande, Vanden Boer, & Demeyer, 2017). Last, also many organisational factors determine the burden of care, such as waiting lists, insufficient information, changing personnel, vacation periods, lack of time and work pressure. In line with this, family caregivers need sufficient information and knowledge about the care landscape, and about which types of support exist (Scheepmans *et al.*, 2004).

1.3.5.2 Consequences

Family caregivers who are confronted with a high burden of care can experience severe physical and emotional exhaustion, which has a detrimental effect on the health of the family caregiver. In this respect, research demonstrates that family caregivers have more physical and emotional health problems than people who do not provide family care (Van Audenhove & Declercq, 2007). Besides these health problems, family caregivers also have the risk of neglecting their own life, family and friends by having less time and less moments to relax (Scheepmans *et al.*, 2004). Indeed, the burden of care also has social consequences. It for example negatively affects the relation within the own family (Van Audenhove & Declercq, 2007), and it can moreover lead to social isolation, which relates to feelings of loneliness. With respect to the latter, the psychological, emotional and physical burden of providing intensive and long term family care, in combination with decreasing social contacts with friends (~ social isolation), might result in feelings of loneliness (Vlaamse Ouderenraad, 2019b). In this respect, research shows that for 13% of the family caregivers who do not live in and 21% who live in with the senior in needs family care results in less contact with their family. Both groups respectively also indicate that they see their friends less often because of the family care (respectively 19% and 39%) (Vermeulen & Declercq, 2011). Based on the analyses of SHARE data, we find that Belgians of 65 years or older who gave support during the previous year with personal care and practical chores to household members (in practice this often refers to their partner) in 2015, are significantly lonelier (29%) than those who did not gave such support (17%). Interestingly is that in 2015 people who look after their grandchildren are less lonely (20%) than those who do not (31%), and that the prevalence of loneliness decreases with an increasing number of people they help outside the own household (from 26% who gave help to nobody to 15% among those who helped three people) (De Witte & Van Regenmortel, 2020). These are clear indications that helping others outside the own household (which is more often a positive choice) might be positively related to loneliness, while helping people in the own household, often forms a burden which leads to higher loneliness levels.

1.3.6 The needs of family caregivers

As research shows, providing family care is not always easy and is often accompanied by a burden of care. In this respect, family caregivers have various needs that could be fulfilled to lower that burden of care.

First, family caregivers have a need for more integrated information and advice about how to fulfil their role, and they would also benefit from administrative simplification (Studiedienst Socialistische Mutualiteiten, 2016).

> *'The qualitative analysis indicates clearly that all interviewed family caregivers receive too little advice and support from professionals from the health care sector to find the appropriate services, take the right steps and receive advice about the illness.'* (Cès *et al.*, 2016, p. 60).

Also, more integrated information could take away the fear of many family caregivers when they feel obligated to provide and organise qualitative care (Anthierens, Willemse, Remmen, Schmitz, Macq, Declercq, Arnaut, Forest, Denis, Vinck, Defourny, & DFarfan-Portet, 2014). In general, family caregivers lack a reference person who guides, informs, and supports them on a regular basis (Cès *et al.*, 2016). Although family caregivers find medical practitioners the most suitable actor in this respect, the latter often limit themselves to the medical domain (Cès *et al.*, 2016). Moreover, the authority aspect makes that many family caregivers are passive in their relation with professionals, through which they not always dare to ask for help and advice. This is even more difficult for socially and economically vulnerable people (Cès *et al.*, 2016). Therefore, it seems important to detect family caregivers in a vulnerable situation through a proactive, outreaching method in order to inform them (Vlaamse Ouderenraad, 2016).

Further, various structural barriers should be taken away which impede the provision of durable family care. In this respect, family caregivers need sufficient support from both formal and informal care services such as home care, residential care, respite care and volunteers (Studiedienst Socialistische Mutualiteiten, 2016). Indeed, research shows that many family caregivers would benefit from more respite care (e.g. day care and sitters) and about 20% of the family caregivers need more professional home care (Vermeulen & Declercq, 2011). In this respect, *occasional* home care, day care and short-term stay should be made more easily accessible, for example also at night and in the weekend. This is important because 52% of the family caregivers state that it is difficult to combine a professional job with family care, and 20% of the family caregivers no longer want to work due to the care situation. To make this possible, various job-settlements could also be stimulated such as early pension and part-time work (Studiedienst Socialistische Mutualiteiten, 2016). Next, professional care should be sufficiently qualitative, accessible and affordable (especially for lower incomes) (Vlaamse Ouderenraad, 2016). Making professional services affordable can counteract the fact that many family caregivers wait too long to ask for professional help (Vlaamse Ouderenraad, 2016). In this respect, research shows that the cost of home care leads to difficulties in 6% of the cases, which are logically concentrated among users with a low income. The latter report in almost 25% of the cases problems to pay for the home care (Studiedienst Socialistische Mutualiteiten, 2016). Financial support is also welcomed by family caregivers themselves, of which about 20% have difficulties making ends meet (Vlaamse Ouderenraad, 2016). Other research shows that about 40% of the family caregivers that live in with the senior indicate having difficulties making ends meet (Vermeulen & Declercq, 2011). Hereby, many family caregivers do not make use of subventions because they are not well known and because they depend strongly on the municipality (Vlaamse Ouderenraad, 2016), which again emphasises the importance of integrated information. However, hereby the effect of subventions is not straightforward: while family caregivers who receive a reimbursement for their support feel more valued, they at the same time feel more pressure to perform qualitative and sufficient care (Bronselaer *et al.*, 2018). Further, also the general coordination between different forms of care could be ameliorated, according to the family caregivers (Vermeulen & Declercq, 2011). Last, since we have seen that professional support can in fact increase the burden of care, it seems important to ameliorate the relation between family caregivers and professionals. In this respect, it is important to strengthen the knowledge, appreciation and competences of the professionals (Scheepmans *et al.*, 2004), because it would lead to a better collaboration. Indeed, we have already seen that they sometimes show little involvement, have a lack of attention for the family and even sometimes blame the family for certain problems (Van Audenhove & Declercq, 2007). Reversely, family caregivers should be recognised in their role by professionals, for example by giving them a clear place in multi-disciplinary discussions and by recognising them as equal actors (Vlaamse Ouderenraad, 2016). Also, family caregivers should learn to deal with the decrease of autonomy and privacy, once there are professionals in play (De Koker, 2018).

Last, research shows that 11% of the family caregivers would welcome more psychological support. Indeed, there are suspected feelings of depression among 20% of the family caregivers who do not live in with the seniors, which amounts to 36% among the family caregivers who live in (Vermeulen & Declercq, 2011). In this respect, psychoeducation could be effective for many family caregivers to learn about specific illnesses (e.g. how to deal with dementia). Further, also self-help groups would be useful for their general wellbeing by giving them emotional support and by giving them the feeling that they are not alone in their situation. Nevertheless, we observe that only one out of ten family caregivers in Flanders is part of an organisation that gives information and formations to caregivers (Cès *et al.*, 2016).

In sum, family caregivers need more structural support on various domains because it would result in a decrease of the burden of care. Indeed, such support could help to avoid social isolation and feelings of loneliness (e.g. through a sufficient offer of respite care, sufficient information about possible support), strengthen their psychological and physical wellbeing, and enhance the quality of the relationship with the senior (Vermeulen & Declercq, 2011).

1.4 Seniors and their family caregivers during the COVID-19 pandemic

1.4.1 The emergence of corona

Begin 2020 the world was suddenly struck by the COVID-19 crisis, a pandemic that holds the whole world in a chokehold. In Belgium, this crisis (which originated in China) started getting attention from the media in January, and only in February policy makers and journalists started to understand the gravity of the situation. In March, various measures were taken by federal and regional governments to push back the virus, by limiting the social contact between citizens. Indeed, in Belgium a lockdown was installed on 13 March 2020 (Steyaert, De Wachter & Dely, 2020), which meant that citizens in general were no longer allowed to physically go to their workplace (but had to work from home), could no longer visit friends and family in residential facilities for elderly people and could no longer come together with friends and family in their homes. People were mainly allowed to do outside sport activities (with other people), do their groceries and go see their doctor. In general, this led to decreasing social contacts for all Belgian citizens during several months, and also the contacts themselves changed. Indeed, Belgian citizens needed to wear masks, sneeze in their sleeves, hold 1.5 meters distance, apply strict hygiene standards, ... At the end of May, in most European countries some of the restrictive measures were slowly phased out: schools opened again in part, restaurants and bars could open under certain restrictions, just like many sport activities (Steyaert *et al.*, 2020).

1.4.2 Social relations

During this COVID-19 crisis it became abundantly clear that social relations, just like food, nature and health are one of the primary necessities in life. Indeed, humans are social beings who need to be in contact with others to give meaning to life (De Witte & Van Regenmortel, 2019a). Nevertheless, the COVID-19 crisis put exactly this primary necessity under pressure because we all saw our social contacts decrease drastically: colleagues, friends and family, the stall keeper at the local market, our neighbours, ... and also family caregivers. Not surprisingly, there are many indications that feelings of loneliness and social isolation are on the rise during this pandemic, which is problematic since loneliness is strongly related to various physical and mental health problems. The years before the COVID-19 crisis, roughly 10% of the Belgian citizens felt 'often to always' lonely, and another 20% felt 'sometimes' lonely (De Witte & Van Regenmortel, 2020). Presumably, this latter 20% felt more often lonely during the corona crisis.

In this respect, many single seniors who in pre-COVID-19 times only had contact with their colleagues or local stall keepers, did not see anybody during several weeks. At that moment, it becomes very quiet, despite various initiatives such as the emergency line, the suicide line and professional psychological support. Further, in many residential facilities for elderly people in both Belgium and the Netherlands there are also indications of the severe impact of social isolation on the lives of the residents, such as physical decline, depression, apathy, behavioural problems, fear, and a general decline in health. Interesting in this respect is that this effect is less present among people with dementia (Steyaert *et al.*, 2020). Moreover, the negative psychosocial side effects of the corona crisis and the restrictive measures will presumably continue to persist while the health crisis is ending. Therefore, the Flemish Minister of wellbeing proposed in this period a plan to strengthen the mental wellbeing of our citizens, and stated that he wants to invest more in 'Caring Neighbourhoods' (Zorgnet Icuro, 2020).

To better deal with increasing social isolation and feelings of loneliness among seniors, various divers and innovative (often technological) solutions were searched that try so sustain social relations, such as video calls, family visiting seniors at the window, personalised postcards were sent, ... Despite this good intentions, many seniors do not have internet access or smartphones, nor the knowledge to use these devices. Furthermore, for people with dementia it is for example difficult to understand video calls, certainly when they involve multiple participants. However, some seniors do applaud these initiatives because they prefer other ways of communication than personal face-to-face meetings out of fear of contamination. Indeed, certain forms of communication with professionals, friends and family (e.g. telephone, video calls, email) were experienced as less threatening. Hence, it is important that social workers in the future listen more to the wishes of the seniors in this respect (Steyaert *et al.*, 2020).

1.4.3 Family care and professional care

The restrictions that were imposed by the Belgian and regional governments aimed to decrease the risk of contamination, which is especially important for seniors. Indeed, vulnerable seniors are frailer, have less resistance than younger generations and are characterised by a higher degree of comorbidity, which makes them a risk group. In this respect, we observe that while the chance to pass away from corona (at the moment this report is written) lays between 0.52% and 0.73% for women and men, this amounts to 4.0% for female and 6.7% for male community-dwelling seniors of 85 years or older (Steyaert *et al.*, 2020). Nevertheless, these restrictive measures also had many negative side effects through which the (social) lives of many vulnerable community-dwelling seniors changed drastically. Indeed, the corona-measures possibly had an even bigger impact on the lives of various vulnerable groups than the virus itself (Steyaert *et al.*, 2020).

First, informal social contacts not only fulfil various social needs, but also support those seniors in various other life domains. Indeed, their confidants who take on the role of family caregivers often support them with practical, physical, emotional and various care needs. When these contacts temporarily decrease or fall away, not only their social function but also their support function on these other domains is temporarily put on hold. The same happens with all the volunteers who were no longer able to fulfil their role (Steyaert *et al.*, 2020). Second, the COVID-19 crisis also affected the professional care and support for seniors with care needs. Indeed, in some instances the professional support and care (e.g. home care and nursing, household help, cleaning aid, residential centres) decreased in intensity due to reasons that lay within the providers of those services. In other instances, seniors were scared to be contaminated by those same professionals through which they themselves ceased those services. Nevertheless, the result is the same, namely that support was not realised to the same extent nor in the same manner during that period. Besides the support, also the 'talk' with those professionals decreased and changed because of the face shields, masks and because home care professionals often had to ask the seniors to stay in another room while they were working to ensure sufficient physical distance (Steyaert *et al.*, 2020). This is problematic because research shows that many seniors with care needs who live alone find this one of the most important aspects about the home care. In this respect, some researchers state:

> *'An important observation about the past period is that care not only includes medical care, but that also attention, social contact and involvement pertain to the core of good health and services. This aspect should be taken up during conversations about the organisation of care and about the future installation of care.'* (de Boer *et al.*, 2020, p. 12).

On first sight, there appear to be mainly negative side effects of the restrictive measures, which is presumably reinforced by the overwhelming negative image in the media of corona. A director of a residential facility for elderly people in Flanders:

> *'The news media called us, and asked us how it went in our residential facility for elderly people. After I told them that it went well, little contaminations, still good care, they told me that they heard enough of those stories, and would go find something else. But all those other good stories I sadly did not saw in the media.'* (Steyaert *et al.*, 2020, p. 32).

However, we observe that these measures also have had some positive consequences. Indeed, there are for example indications that the bond between personnel and residents of residential facilities for elderly people became stronger and warmer during this period. Moreover, some residents of those facilities became calmer and more independent because many visits fell away, which could result in too much stimuli (Steyaert *et al.*, 2020).

1.4.4 Vulnerable groups during corona

We can presume that the effects of the restrictive measures depend on the specific group, and that these effects were more severe for vulnerable seniors**.** Indeed, seniors with dementia for example are often disorientated in both time and space, do not recognise the difference between day and night and lose their normal rhythm, which in combination with the quarantine and their medication could result in a higher risk for 'delier'. The latter refers to temporary psychological effects such as being confused and hallucinating due to physical changes or changes in the environment. In this respect, the personnel with their protective material were sometimes seen as threatening, and the halt of visits as a punishment (Steyaert *et al.*, 2020).

Next, we can also presume that the situation for single seniors with care needs and who live alone was more difficult to bear because they had to deal with the decrease in formal and informal support on their own. Indeed, during this period, they themselves had to take over those tasks or those tasks were not done by anyone.

Further, we can also presume that the family caregivers who live together with a senior with care needs had to take over many of those tasks. Given that the scientific literature shows that family caregivers were already before the COVID-19 crisis confronted with 'a burden of care', we can presume that this care burden further increased during this period. Indeed, they probably took over many of the tasks that before were done by professionals and volunteers. This increase in tasks and responsibilities may have resulted in a higher physical and emotional burden among family caregivers, just like more feelings of loneliness because those family caregivers presumably had less time to rest (Vlaamse Ouderenraad, 2020b). In this respect, they clearly missed the respite care, thanks to which they could regain some energy by having some time for themselves. Further, family caregivers also had many questions and were confronted by feelings of fear, anger and worries. Indeed, they needed to find a balance between the quality of life of the senior (visits, organisation of practical chores) and applying the restrictive measures. Indeed, difficult choices had to be made: can we still see the seniors, go for a walk with them, ...? Also for various family caregivers around the same senior, communication was needed which was not always easy (Steyaert *et al.*, 2020).

1.5 Conclusion

Based on our literature study we conclude that due to ageing, older seniors structurally form a bigger part of our total population. While at the moment there are about 330,000 seniors of 85 years or older in Belgium, this will amount to 830,000 in 2070. Moreover, the overwhelming majority of seniors of 80 years and older still live in their own home, and want to stay there even when they become dependent on care. At the moment, about 40,000 people with Alzheimer for example still live in their own home. Therefore, it seems a good time to rethink and recalibrate the care system and to study how society can better play into the needs of community-dwelling seniors, and enhance their physical, social and mental wellbeing.

In this respect, the concept of ageing in place comes to the foreground, which implies *'meeting the desire and ability of people, through the provision of appropriate services and assistance, to remain living relatively independently in the community in his or her current home or an appropriate level of housing'*. This requires an integrated, holistic approach that focuses on all life domains within the local neighbourhood such as social participation, mobility, housing, wellbeing and health. With respect to the latter, the place of both formal and informal care is very important for older community-dwelling seniors, who are confronted with various vulnerabilities on the social, physical and psychological domain. Hereby, it is also crucial to recognise the limits of informal care, for both seniors and family caregivers.

With respect to the seniors themselves, it is important to realise that not all seniors can appeal in the same extent to informal care: vulnerable groups (e.g. older seniors, people who live in poverty) have fewer possibilities to appeal to an informal care network, through which professional care becomes even more important for them. Hence, everybody should be able to use professional help without any feeling of guilt, and informal care should be a positive choice of both the senior and the informal caregiver. With respect to family caregivers, we see that Flanders alone counts about 600,000 family caregivers, and that the yearly economic value of family care is estimated to be about 22,3 billion euros in Belgium and 11,4 billion euros in Flanders. But despite its many positive effects, family caregivers are often confronted with a burden of care, which can manifest itself of various domains: the social (e.g. social isolation, conflictual relationship), psychological (e.g. more depression, fear, feelings of loneliness), physical (e.g. exhaustion, higher mortality), emotional (e.g. worries) and financial domain. This burden of care is determined by the intensity of the care, internal sources (e.g. personality and quality of relationship between senior and family caregiver), external sources (e.g. formal complementary care), the type of care relation (partner, children) and the voluntary character of the support. This burden of care can not only lead to physical and emotional exhaustion (which has a negative effect on the health of family caregivers), but it may also result in family caregivers having less free moments to relax and more difficulties to sustain their own social network. As a result, family care can result in social isolation and feelings of loneliness. Therefore, it is essential to take the various needs of family caregivers sufficiently into account such as more integrated information, administrative simplification, sufficient formal care for the senior, psychological support for the family caregiver, ... Only that way, the burden of care can decrease, which will have positive effects on both family caregiver and senior. Indeed, family care should not result from a moral duty or characteristics of the environment (e.g. no place in residential settings) because then the burden of care increases. Ideally, family care is a choice that is based on motives such as love and affection.

The emergence of COVID-19 and the restrictive measures taken by the Belgian governments to contain this virus, presumably have an enormous impact on the lives of both older seniors and their family caregivers. These measures that started in the course of March 2020 aim to limit the number of physical contacts between people. Despite many divers and innovative (often technological) ways that aim to sustain social relations, there were several indications that more people were confronted with social isolation and feelings of loneliness during this period. This is worrisome given that loneliness is related to various physical and mental health problems. Further, the informal family care presumably decreased, through which those seniors were less supported with various practical, physical, emotional and various care needs, but also much of the social contact fell away. Similarly, the professional care presumably also decreased in intensity and provided differently (e.g. not being in the same room as the senior while working), through which certain functions of that care (e.g. the talk) were less fulfilled. However, in some instances, these COVID-19 restrictions have also led to positive outcomes, such as a better bond between residents of residential facilities for elderly people and professionals. Nevertheless, we can suppose that the effects of the restrictive measures strongly depend on the specific group, and that these effects were more severe for vulnerable groups such as older seniors with care needs and their family caregivers, who were already confronted with vulnerabilities on various domains.

2 | Method

2.1 Research question and relevance

This study investigates following research question:

How do the measures taken to deal with the COVID-19 pandemic affect the life and care situation of community-dwelling older seniors with care needs and their family caregivers?

First, this research question is relevant because our literature study shows that in Flanders and Belgium relatively little is known about the impact of COVID-19 on the lives of community-dwelling seniors with care needs and their family caregivers. Hereby, we can suppose that the restrictive measures taken to handle the COVID-19 crisis make the life and care situation of both seniors and their family caregivers in many instances more difficult. Both actors seem to be alone more than ever, have more tasks, responsibilities, and less support. How do seniors with care needs and their family caregivers deal with this situation?

Second, research shows that although much is known about informal care and family care in general, we know little about how seniors themselves look at the family care that is given to them. Indeed, the perspective of the seniors is often lacking in research.

> *'Therefore it is recommended that future research concentrates on the experiences of seniors, family caregivers and care professionals about the current care to gain insight into this before, during and after the corona crisis, and so improve people-oriented care, also in times of crisis.'* (van Boekel, Stoop & Luijkx, 2020, p. 1).

In line with this, relatively little is known about how people share the care for a vulnerable senior.

> *'Although a number of studies involve both the family caregiver and the person in need from the same care situation, the reciprocal perspective within those dyadic relations remain insufficiently investigated.'* (Bronselaer *et al.*, 2018, p. 46).

Third, although the average age of family caregivers increases, an extensive review shows that in Flanders there is a lack of knowledge concerning older family caregivers (of 80 years or older) who care for their partner. Not only do those older family caregivers often need support and care themselves, but the seniors for who they care also have higher needs because of increasing cognitive and physical problems due to their older age. Moreover, they are characterised by a shrinking social network through which formal support becomes increasingly important, and which might form a hazard in the background of the 'socialisation of care'. Therefore, it is interesting to gather more information about their support needs, specific vulnerabilities and difficulties, if their lifestyle can continue (given the care they offer), when and why they take the step to go to residential care, why they do (not) make use of professional care, ... (Bronselaer *et al.*, 2018).

2.2 Data collection and data analysis

To answer our research question, we conducted semi-structured interviews with older seniors and their family caregivers. Indeed, this is an appropriate method to gain information about how vulnerable and less easily reached groups such as older seniors with care needs experience the family care they receive. *'Especially qualitative data collection is promising as a complement to existing quantitative data.'* (Bronselaer *et al.*, 2018, p. 67).

Hereby, we focus on older community-dwelling seniors (i.e. seniors of 80 years and older) with care needs because we presume that they are more negatively affected by the restrictive measures taken by the government, as a result of their higher vulnerability on various (physical, social and psychological) domain. However, since we know relatively little about the impact of the restrictive measures on the lives and care situation of seniors, we try to reach a broad spreading with respect to their dependency and the type of support they receive. With respect to their dependency, we simply premise that they make use of some kind of professional support: from less intensive support such as cleaning help, doing groceries or providing company, to more intensive types of support such as home care, sitters and day care centres. Consequently, we neither make a distinction between the sort of support they need or receive, according to their type of dependency (IADL, ADL). Further, with respect to the family caregivers, we also try to include a wide range of family caregivers, which consequently can refer to the partner, children, family members or friends. Indeed, here as well we try to gain a broad understanding of the impact of the restrictive measures on the lives of a wide range of family caregivers.

In order to obtain the contact information of a number of respondents, in the spring of 2020 we contacted various organisations that offer professional care in one specific Flemish province and Brussels. A number of organisations refused to participate to the research project because of an exceptionally high workload through which they preferred prioritising their actual work or because their participants did not feel like participating due to 'the hell' they went through. In addition, a number of care organisations simply did not respond our mails. Nevertheless, through the willing support of seniorama, Familiehulp/Samenferm and ZorgLeuven, we obtained the contact information of a number of community-dwelling seniors with care needs, and who receive support from at least one family caregiver. While the first organisation offers various services for seniors, which are mainly based on volunteers such as providing company, the two latter organisations offer professional services such as home care and cleaning services. In this respect, we asked the coordinators of those organisations to ask some community-dwelling seniors (of 80 years and older) of who they know that they also receive support from at least one family caregiver, if they are willing to participate to this research project. If this was the case, we contacted those respondents by telephone, and explained the research project in more detail and asked them if they were willing to give an interview. We also immediately asked them if they had a family caregiver that we could contact with the question if they were also willing to participate to this research project. If this was the case, we contacted those latter and made an appointment. In a number of instances, the coordinators of the care organisations gave us the contact details of some family caregivers (of seniors of 80 years and older), which we subsequently contacted.

In total we interviewed 21 respondents, of which eleven seniors with care needs (of 80 years and older) and ten family caregivers. Hereby, we spoke to seven pairs (of senior and his/her family caregiver), and seven respondents without a counterpart. Two of the seven pairs consisted of a couple, three of a parent and daughter, one of a parent and son, and one of a senior and her friend. Of the seven respondents without counterpart, there were four seniors (who did not feel comfortable asking their family caregivers to participate to the research project), and three family care gives (of which two counterparts were not interviewed because of a high state of dementia and one because the senior was unwilling to cooperate). In total, there were seven female seniors with care needs and four male seniors with care needs.

All the interviews were conducted in June and July 2020, took about one hour and were done in the place where the respondents felt most comfortable with. For all seniors with care needs and most family caregivers this was in their own home. Some family caregivers came to the institution of the researcher for the interview. The interviews were recorded and transcribed verbatim. Next, we applied a thematic content analysis which was based on our study of the scientific literature: we used the themes and concepts we derived from the literature (concerning family care, older seniors, COVID-19), and expanded this with the information that emerged from our interviews. Through this iterative process, the first author labelled the interview transcripts based on the concepts derived from the literature. That way, the literature functioned as 'sensitising concepts' by offering a reference point and guidance to analyse our empirical data.

> *'Whereas definite concepts provide prescriptors of what to see, sensitising concepts merely suggest directions in which to look. Sensitising concepts [...] do not have a full operational definition, and leave room for the researcher to find out how the concepts manifests itself in the data.'* (Janssen, 2013, p. 46).

In what follows, we present interview quotes to illustrate various concepts or ideas, and we provide 'thick description' of the studied context and meanings expressed by participants so the readers can assess the potential transferability of the results to other settings. This guarantees the external validity of this study (Janssen, 2013).

2.3 Ethical considerations

Before conducting the interviews, we obtained all the necessary approvals of the authorised ethical and privacy committees at the university level. In doing so, we not only assure to be in accordance with all the requirements of data protection of the authorised instances of the KU Leuven, but also that our research project fulfils all ethical considerations of the authorised ethical committee of the KU Leuven (these authorisations can be requested by mail). In order to obtain these permissions, we needed to describe the most important considerations of this research project in detail, and the way we would elaborate this project. This was not only necessary for the privacy and ethical considerations, but also with respect to the possible risk to contaminate the respondents in the context of COVID-19.

After an explanation by the researcher of the various advantages and risks of participation to the research, all respondents signed an informed consent document. Hereby, they were told that they could stop the interview at any time. Further, we removed the names and other personal characteristics to ensure anonymity, and the transcripts that were all given a code to further safeguard anonymity, were not shared with anyone during the research project. In addition, in order to minimise the risk of possible COVID-19 contamination, the interviewer at all times applied strict hygiene standards, wore a mask and held more than 1.5 meters distance between him and the respondents. Last, we gave the respondents information about the existence of possible professional support in their neighbourhood to which they could appeal, and after publication we send them the final research report (on request) to thank them for their participation.

3 | Results

In this chapter, we discuss our research results. In a first paragraph, we stand still at a number of difficulties seniors of 80 years and older are confronted with: the death or separation of their partner, health limitations, feelings of loneliness and difficulties to remain living in their own home. In the second paragraph we discuss the formal and informal care older seniors receive, from the perspective of the seniors. In the third and fourth paragraph, we stand still at the assessment of the care situation, respectively by seniors and family caregivers. In the fifth paragraph, we discuss the impact of the restrictive measures taken in the background of the COVID-19 crisis on the lives of seniors and family caregivers, and last, we present the keys for a happy life according to the seniors.

In the course of this chapter, we also include some best practices and examples of interventions that try to formulate solutions to specific difficulties both seniors and family caregivers are confronted with, and which aim to increase their quality of life.[1]

3.1 Difficulties of older community-dwelling seniors

In this paragraph we discuss the difficulties seniors of 80 years and older are confronted with, and which have a strong impact on their lives. In this respect, we see that the quality of life of older seniors is affected by the death of their partner, various physical and psychological health problems, feelings of loneliness, and difficulties staying in the own home while being unwilling to move to a suited residence.

3.1.1 Death or separation of the partner

Several respondents explain how the passing away of a partner has a detrimental effect on the quality of their lives. One older seniors' husband was for example in a high state of dementia through which he had to go to a nursing home. From that moment on, his wife was confronted with the difficulties of reorganising her life independently and taking all big and small decisions alone again, for the first time in many decades. This situation even resulted in her taking care less of her own personal hygiene and household, losing interest and joy in life, and having less general strength to continue living (e.g. no longer wanting to eat with her family). Her daughter says in this respect: *'I just think she no longer felt like it because her life was not here anymore since my father was there [in the nursing home].'* (Respondent M8).

3.1.2 Physical health limitations

A second factor that strongly affects the quality of life of seniors are health problems. First, many seniors are affected by physical health problems which limit their possibilities to do various activities. Indeed, some seniors do not hear (Respondent 2) or see well (Respondent S2, S14), by which they cannot longer watch television (Respondent S19), are afraid to go outside on their own and are no longer able to call people (Respondent S11). Because of the latter, some respondents explain how they are no longer able to organise the care they need because they cannot talk to professionals on

---

[1] In this chapter, we regularly present references to specific respondents. Hereby, the S refers to seniors with care needs, and the M refers to family caregivers (who can also be a senior).

the phone to discuss practical issues (Respondent M6). Moreover, sight problems make that they can no longer recognise people they know on the street (Respondent S11).

Further, a number of seniors explain having difficulties to walk (Respondent S2, S19, S14). As a result, they are scared to go outside on their own because they could fall (Respondent S10, S13, S4) and always needs somebody that accompanies them when they go outside (Respondent S14, S13). The latter strongly increases their dependency of other people, and makes that many seniors no longer go outside very often. One respondent did not go outside for more than a month due to her physical health problems. As a result, she also stopped volunteering because she was no longer able to go to the building on her own by public transportation (Respondent S10). In line with this, another respondent explains that he is not able to take the bus with his 'walker', because it is impossible for him to lift the walker when he gets in or out of the bus (Respondent S2). Besides the public transportation, the sidewalks are also seldom adapted to the needs of seniors who use a walker or who are in a wheelchair. Indeed, the sidewalks often form an obstacle to go outside, which severely increases their dependency because they can no longer go outside on their own (Respondent S17, S2, M9). One respondent explains that this is the reason she no longer goes to the church in her neighbourhood (Respondent S17). *'It has always bothered me; they never paid attention to the sidewalks. [...] For somebody in a wheelchair it is impossible to go to the centre of the city.'* (Respondent S2).

Besides the practical difficulties to talk to people on the phone and go outside on their own, these physical limitations are also difficult to accept emotionally:

> *'It is not easy. Because with all those limitations, you sometimes notice that something needs to happen or I could do something, and that it is no longer possible.' (Respondent S14). Another respondent: 'Look now, I used to be able to do that, and now I can no longer do it. [...] I find that difficult sometimes, yes I find that difficult. [...] Accepting, that is the worst.'* (Respondent S21).

In this respect, the impact of those limitations on the quality of their lives is strongly determined by their financial means and the neighbourhood. Hereby, the own home is for example an important factor. While some respondents live in a small apartment without terrace, others live in a house with a big garden where they can relax, and which makes their physical limitations more bearable (Respondent S4). Further, the specific neighbourhood is also an important factor. Indeed, some respondents explain that they live in a street or neighbourhood where there is very little movement, little things to see and no services in proximity (Respondent S17). Further, many seniors appeal to material aids such as having a lift installing in their home to go upstairs (Respondent S2, S19, M15), a walker (Respondent S14), an electric wheelchair (Respondent S4), reading aids (Respondent S14), a parking card for people with a handicap (Respondent 2), an alarm brace (Respondent S2, S19, S17), an electric bed (Respondent S17). In addition, some seniors explain how they adapted their home to their specific needs, for example by living and sleeping on the ground floor (Respondent S17), or installing a lift: *'When you have the money, then it does not matter, then you are not unhappy. Then you say: I will go upstairs, I will go to bed, and you just need to push the right button.'* (Respondent S4).

3.1.3 Feelings of loneliness and limited social activities

Many respondents explain that their life world mostly involves their immediate surroundings such as their own home and local neighbourhood, which is also substantiated in the scientific literature. Not seldom, older seniors only have contact with only a limited amount of people (friends, family and/or professionals) (Respondent S16, M7, M6), and several respondents explain that they do very little activities. When we ask a certain respondent what she does during the day: *'More sleeping than anything else.'* (Respondent S11). In line with this, several respondents indicate that they regularly deal with feelings of loneliness: *'Always being alone, it's not pleasant.'* (Respondent M6). A family caregiver who thinks her senior father feels quite lonely: *'Yes, he can complain about those little things and then become angry* *and very frustrated. That I think there must be somethings else behind it.'* (Respondent M3). Although her father himself says he does not feel lonely, he does mention that he would in fact like his family to pass by more often and ask how he is doing which indicates some feelings of loneliness (Respondent S2).

3.1.3.1 Causes of loneliness

The feelings of loneliness of these older seniors have multiple causes: the death or separation of the partner, the death of friends and family, characteristics of the neighbourhood and geographical proximity of the close ones, physical health limitations, personality traits and accepting the own vulnerability.

a) Death or separation of the partner

From a previous report we know that:

> *'An intimate relationship with a partner, just like relationships with family and friends can offer practical and emotional support, but is especially important because it can create a feeling of love and belonging. Therefore, having a partner is crucial because a lack of (qualitative) relations is associated with feelings of (emotional) loneliness.'* (De Witte & Van Regenmortel, 2019b, p. 38).

In this respect, a number of respondents (Respondent M6, M8) feel emotionally lonely since the death or separation of their partner, which refers to emotional loneliness (i.e. 'the absence of a meaningful, intimate and exclusive relationship') (De Witte & Van Regenmortel, 2019a). *'Let me put it like this: I do not miss a woman, but I miss my woman.'* (Respondent S2). Another respondent also feels emotionally lonely since the divorce with her husband already many years before, and explains that she misses affection (despite volunteering and seeing her family regularly).

> *'When I wake up in the morning for example, and my back hurts or I did not sleep well, then sometimes I think: if only I had somebody to talk to. [...] That is more the comparison with before. [...] That you can say something in confidence, or that you can solve things together. Now, I have to do it alone. [...] For example, imagine I have a bad day [...] If you still have a husband you can tell him. But I need to keep everything for myself. [...] Because you now see that you need each other. When you are young, you do not really need each other. [...] Now I have to go alone. [...] But then, you see those couples walking there and then you think: "yes, I could have been walking there". But it is not like that. You have to accept it. I accepted it; it is already such a long time.'* (Respondent S21).

Still another respondent whose husband lives in a nursing home (due to his dementia) no longer wants to have pleasure without her husband (e.g. no longer wanted to see her friends), and only rarely wants to see her close family member. Despite the fact that she visits her husband every day in the nursing home, she feels very lonely according to her daughter (Respondent M8). Her daughter:

> *'Despite the fact that they had friends who always called her and proposed to come over to drink a coffee. No, the last 18 months her day consisted of [...] waking up in the morning, taking breakfast, then they brought her meal [...] At 2 pm a taxi came to pick her up and bring her to the nursing home, and at 6.30 pm the taxi picked her up again and brought her home again. Then, she watched television and went to bed. It was like that five days a week.'* (Respondent M8).

In line with this, a respondent explains that after the death of his father, his mother does not want to look for new social contacts, despite her feelings of loneliness. He states that she is not flexible in that respect: although she went a few times to a meeting centre in her neighbourhood, she stopped going because she is not interested in other peoples' lives (Respondent M6). The latter two examples show that after the death of their partner, two respondents also strongly limited their other social contacts, which presumably also has a negative effect on their social loneliness.

b) Passing away of friends and family

Our previous research report has demonstrated that *'positive relations with family and/or friends form a source of strength, which helps them to maintain mastery over the determinants of their lives.'* (De Witte & Van Regenmortel, 2019b, p. 38). In this respect, many respondents mention that they feel lonely because many family members and friends died over the years (Respondent S2) and various social contacts decreased. This refers rather to social loneliness (i.e. the lack of an adequate, broad social network of friends and acquaintances) (De Witte & Van Regenmortel, 2019a). *'When you get older, friends.. One after the other passes away.'* (Respondent M15). *'I have nothing, nobody.'* (Respondent S13). One respondent thinks that his mother feels quite lonely *'Because she does not see a person every single day, and she is alone for already 22 years. [...] So her network around her is disappearing with growing older.'*, because people die or move (Respondent M18). His mother confirms: *'Yes that is all gone, I have no social network left.'* (Respondent S17). Another family caregiver explains that his mother is often nostalgic and talks about the past: *'Before it was better. But, for her it was indeed better, because she, they [his parents] never had any other contacts outside the own family. [...] Now, there is no more family [they all passed away].'* (Respondent M6). A senior states that although she is used to be alone, she severely misses to have a friend:

> *'I am used to be alone. [...] That is 21 years ago that my husband passed away. [...] Difficult to be here alone? No. That is nothing to me, I tell you, I am already alone for such a long time. [...] I got used to it [...] What is a shame that is.. I have no friends. If I would have a friend.. than.. you have the chance to talk.. like an old lady. Talking about the old days, I miss that. Before, I had a friend in [a city far away], so I visited her often, and she sometimes came here, but she also grew older. And also our health.. So she no longer comes here, and I no longer go there.'* (Respondent S11).

Last, one respondent who goes to eat her meal every day in a social organisation where she meets many other seniors who become friends and/or acquaintances, has many difficulties when regularly some of those seniors pass away (Respondent M12).

c) The neighbourhood

Living in a remote neighbourhood where there is little to do and where there are little neighbours in proximity, has an indirect impact on feelings of loneliness of seniors (Respondent M6).

> *'And that is due to the location of the home. When you are in front of the house, on the right hand side, there is a school. That means, it are not really neighbours. [...] From 4pm, there is nobody. On the other side, she has a neighbour [...] who in the meantime has a girlfriend and who is more with his girlfriend than at home. So that house is also empty in fact.'* (Respondent M6).

d) Geographical proximity of friends and family

One respondent explains that it is more difficult to sustain social relations when family members and friends live far away, though which feelings of loneliness also increase: *'So I do not see them anymore.'* (Respondent S11). Indeed, it is important that their social contacts, family and friends, live nearby through which they can more easily pass by (Respondent S14, M6).

e) Physical health limitations

Many seniors are confronted with physical health limitations through which they can walk less easily or no longer hear well, which reduces their possibilities to do many activities and to sustain their social network (Respondent M6, S2). Indeed, one respondent has severe sight limitations which make her almost unable to see, through which she can no longer take the bus alone, and through which she loses her interest to go outside. As a result, she is most of the time alone in her apartment, and many weeks she does not see a single person: *'I have no friends here, I have nobody they are all.'* (Respondent S11, M12). It is clear that these physical limitations have a severe impact on their feelings of loneliness.

f) Personality traits

A certain family caregiver explains that his mother has a difficult character: she lacks flexibility and is difficult to deal with socially. According to her son, this led to problems to create a good bond with her family and only having a very limited social network, which in turn resulted in feelings of loneliness (Respondent M18). Her mother admits feeling lonely: she misses company and talking to other people. She also admits that she does not have a good relationship with her children, and mainly has contacts with the own family and the professionals that pass by. All days are the same, but the weekend is even more difficult because she does not see anyone. *'The only thing I have right now is to visit my daughter [who has a handicap and lives in an institution], but with the lockdown that has been since February. And I find that very sad.'* (Respondent S17).

g) Accepting the own vulnerability

In line with this, although a respondent admits to her family caregiver that she often feels very lonely, she on the other hand does not (want to?) do anything about that situation. Indeed, she seems to have difficulties accepting a new situation, getting to know new people because they do not interest her. She for example did not want to participate to this research project. According to her son, she said: *'No no, that they leave me alone. I have everything I need [...]. I need nothing else, I am good the way it is and the only thing I want is that they leave me alone.'* (Respondent M6). According to her son, she could certainly use the company of some volunteers, but she would first need to accept her vulnerability before wanting to ask others for help. *'If she would have to ask it herself, she will not do it.'* (Respondent M6). From a previous research report of the be.Source Chair we find that accepting the own vulnerability is a source of strength which reinforced resilience of seniors:

> *'[...] it becomes apparent that acceptance of one's own limitations - which is a process that takes time - is an important source of strength which helps elderly to deal with adversities. Indeed, accepting one's own vulnerabilities makes it easier to accept support from others.'* (De Witte & Van Regenmortel, 2019b, p. 33).

3.1.3.2 Strategies to alleviate or prevent feelings of loneliness

Although several seniors state that they regularly feel lonely, other seniors are not lonely at all and explain why this is the case and also mention the strategies they use to deal with feelings of loneliness when they emerge. In this respect, both social relations and doing activities is of crucial importance.

a) Social relations

One of the most important ways to prevent feelings of loneliness is to have sufficient good relations (Respondent S19, S14, M15), which is off course subjective. In this respect, seniors are less affected by feelings of loneliness when their partner is still alive and lives with them (Respondent S4, S14, M15). In line with this, it appears to be very important to have at least one good contact. Indeed, one respondent is very often alone, and only has one real friend with who she has a good contact. Nevertheless, she never feels lonely: *Lonely, no, jamais de la vie.'* (Respondent S10). However, in this respect the social contact with that one friend is extremely important for her. *'When [name of her friend] passes by we can talk, laugh. [...] I always find that pleasant.'* (Respondent S10). She even states that her social relations are the best thing in her life (Respondent S10). This is a perfect indication of the subjective character of loneliness: while some people need many social contacts (in order not to feel lonely), others only need a very limited amount of contacts. Her family caregiver: *'I would find that very lonely, but she does not. She has always known it like that: always being alone.'* (Respondent M9). In line with this, another senior has mainly contact with her cleaning aid, neighbours, and a volunteer who is more friend than volunteer to her.

> *'She knows that. That is such a good mutual understanding. And then, you do not need 10 around you. [...] on who you can count. [...] But I do not feel lonely. [...] I do not know what a depression is. And I do not want to experience it either.'* (Respondent S13).

Further, despite the fact that they no longer can go outside due to physical limitations, a certain couple is not lonely at all because they have many social contacts who live nearby through which they often come and visit (Respondent S14, M15). In this respect, when seniors do feel lonely because they experience that they have too little social contacts, some of them try to organise their professional care that way, so they regularly see somebody. One respondent for example makes sure that one week the cleaning help comes, and the week afterwards the professional home care (Respondent S21). Another family caregiver about his senior mother who feels lonely:

> *'I think all that professional support that she organises is in first instance.. [...] to have somebody at home. [...] My mother can get it all organised [...] But not many people will spontaneously pass by to ask her how she is doing. She has never built such a network around her, of friends and all. And yes, that people who pass by, she will have to pay. [...] I understand that she likes there to be something broken in order for us to come over.'* (Respondent M18).

In this respect, some seniors also explicitly appeal to a volunteer for company (Respondent S17), eat every day in a social organisation together with other seniors (Respondent S11) or take the bus every day to go drink a coffee in a bar in the city centre, in order to see some people every day (Respondent M6). Further, one respondent explains that his mother feels lonely in part because she has no computer through which many communication is not possible for her, for example with the institution where her child with a handicap stays (Respondent M18). Therefore, learning to use such technological devices (e.g. smartphone for video chat) to sustain social contact will presumably also positively affect the social contacts and feelings of loneliness of seniors (Respondent M6).

b) Activities

Besides the social network, it is also very important to have sufficient activities in order to prevent and deal with feelings of loneliness. One respondent admits that he sometimes feels lonely, but says that it is most of the time only of a short duration due to his many interests and activities. *'Lonely? I am too busy. [...] My loneliness is.. that sometimes comes up when you are alone, but that is of short duration. I am way too busy and that makes me happy.'* (Respondent S19). In line with this, many other respondents who say they do not feel lonely, talk about their activities in this respect, such as reading (Respondent S13, S4), watching television (Respondent S13), having projects such as writing a book. *'Because I have too many interests. The days fly by. You are busy with so many things. [...] The day is always too short.'* (Respondent S2). Indeed, the scientific literature shows that activities distract seniors from their feelings of loneliness, which will therefore mostly present themselves at the end of the day when the seniors are alone at home (Respondent S21).

3.1.4 Unwillingness to move while having difficulties to remain in the own home

Several respondents state that it is difficult to remain living in their own home because it is too big to take care of. However, although it would be more practical to move to an adapted residence, they do not want to move (Respondent M6). Even more, almost all of the respondents explain that they would do almost anything to avoid going to a nursing home (Respondent M7, S2, S19, M9). *'I hope that that will remain possible, because when that is no longer possible, I would not want to go to a nursing home. My wish is to stay here.'* (Respondent S17). One respondent thinks nursing homes are horrible, and states that it makes her afraid because the care is very bad (Respondent M9). After a hospitalisation, a few years back which was an unpleasant experience, one respondent said: *'I won't leave my house, and with that experience certainly not. [...] I have always been here.'* (Respondent S2). Another respondent even said:

> *'If I can no longer do this, than it is over for me. You understand? [...] I have the papers ready: I will not go to a nursing home. [...] Then I demand euthanasia. [...] In general I do not complain about the care. But when my father defecated in his pants, he could run around with that for three hours. [...] That was in a nursing home. And I do not want to live like that.'* (Respondent S19).

Further, with respect to service flats, several respondents (both seniors and family caregivers) think that there is no real advantage in comparison to living in their own home because they can get almost all needed support at home (Respondent M6). Moreover, some state that they do not want to be surrounded by only old people. Therefore, one respondent who is since long on a waiting list for a service flat, every year declines:

> *'I will be surrounded by old people. [...] At the moment you can receive much help in the own home. That was not the case before. [...] I would only consider a nursing home when it is really no longer possible otherwise.'* (Respondent S21).

Nevertheless, a family caregiver thinks that his mother at a certain moment will have to go to a service flat or nursing home. *'I think that at that moment we will have to speak about a service flat.'* (Respondent M18).

3.2 Formal and informal care for older community-dwelling seniors

Seniors are confronted with increasing vulnerabilities (on various domains), for which they increasingly appeal to both formal and informal care. This is a process that takes time. Seniors in the beginning try to organise and coordinate the care themselves, and increasingly ask the support of both formal and informal caregivers. A family caregiver talks about his senior mother: *'She gradually build that herself, step by step. [...] Organising care and everything around: she does it all on her own.'* (Respondent M18).

3.2.1 The tasks of professional and voluntary caregivers

> *'If I did not have them [professional home care and friends] [...] I would have been in a nursing home since two years.'* (Respondent S16).

Which and how much professional care seniors receive, depends strongly on their specific care needs. Indeed, the amount of care clearly augments with increasing physical, psychological and social problems.

Due to their physical limitations, many seniors make use of professional cleaning aid (Respondent M8, S13, M6, S11, S4, M5, S21, S2, S16, S17, S14) which becomes physically too difficult to do on their own. Further, some use professional gardeners (Respondent M6, S14) and for their groceries appeal to family members (Respondent S2, M3, M6, S19, S14), volunteers (Respondent S13, S17, S11) or a professional organisation (S16). And while some seniors still do their own groceries, they ask people that pass by to buy heavy things (such as milk and water) or to put the heavy things inside (Respondent M6, S21). Next, some respondents receive regularly general 'home care.' for doing one or more of various tasks such as the dishes, cleaning, ironing, cooking meals, ...(Respondent S21, S2, S19, M7, S16, S10, S13). In some instances, the clothes are washed by the family (Respondent M7). Further, some seniors receive every day their meals at home (Respondent S16, M8, S4, M5), and quite a few receive nursing aid at home (Respondent S2, S19, M7, S16, M12, S4, S14).

As stated before, volunteers often do the groceries of the seniors, but also perform various small practical chores such as accompanying them to the doctor (Respondent S11). In this respect, it is important that professionals and volunteers have a car so that the respondents can accompany them to the grocery store (Respondent S10). And although neighbours sometimes help seniors with small tasks such as putting out the trash (Respondent S10, S17) or small groceries (Respondent S17), they do not seem to take on heavier tasks, which shows the limits in this respect.

> *'I already asked them [her neighbours] when he [her husband] fell out of bed ... Then, you ask the neighbours because on my own I cannot get him back in. Then they come. [...] But I do not think you should ask them often.'* (Respondent M5).

3.2.2 From child/partner to care coordinator and person of reference

When we look at which family caregivers offer support, we see that seniors in general first ask the persons they are emotionally closest with to help them: often starting with the partner, then the children, friends, ... In this respect, the geographical distance is also of the matter. While a certain senior has no less than eight children, he will always call his youngest daughter when he has a practical problem because she lives nearest to him (Respondent S2). Indeed, the respondents clearly state that it is very practical when their family caregivers live nearby (Respondent S14).

With increasing health issues and vulnerabilities, seniors appeal more and more to their social network to gradually take over these coordinating and organising tasks. The differences in support between various seniors show that this is a process that takes much time. One senior for example still does all the coordination, administration and finances herself, but asks help or advice from her son when needed (Respondent M6). Other seniors organise and coordinate the care themselves, but ask their family members to do their administration and finances (Respondent S16, S19, S17, M18, M12, S14). And when it is no longer possible for senior to organise the care themselves, it are mostly family members who take these tasks over entirely, and manage the organisation and coordination of care, and the administration and finances (Respondent M8, S11, M7, M3, S4, M5). *'And as a married person would know, then, it is mostly your wife who coordinates the tasks.'* (Respondent S4).

So, with growing vulnerabilities and needs, the persons of confidence gradually become the persons of reference when the seniors have a specific problem. Then, seniors no longer only ask those family caregivers to support them with the organisation of care, finances and administration, but also with various small and big practical chores and questions (Respondent M6, M8, S4). Then, those family caregivers are for example called when the senior falls and can no longer sleep upstairs, with the question to empty a room downstairs and to install the bed on the ground floor (Respondent S16). Indeed, many family members increasingly do various small (and big) tasks such as cooking meals the seniors can put in their freezer (Respondent 2). In this respect, various seniors indicate that it is very important for them that they can appeal to someone at all times when they need advice or have a small or big problem (Respondent M15, S11): *'If I needed more, I just have to ask. [...] That is important for me.'* (Respondent S16). Indeed, most respondents find it very important to have one person of reference on who they can really count when they have a problem (Respondent S14, S13, M9, S10, S17). *'She knows that I am always here for her. [...] That is very important, especially because she can ask or say everything she wants.'* (Respondent M9). *'I know where I can go for help. [...] That is off course important because you are alone: you need someone on who you can count.'* (Respondent S19). In this respect, seniors find the many seemingly small things that family caregivers do for them extremely important (Respondent M9). A senior explains how she was relieved when one of her children was going to work 80% (instead of fulltime): *'Yes, [...] I was relieved: [...] then there is someone I can ask a little bit more from.'* (Respondent S17). The family caregivers confirm that they are always available by phone for the senior with needs (Respondent M9, M12). One family caregiver calls almost once a day, and sees the senior multiple times a week. This family caregiver thinks nobody else would be able to fulfil her role for the senior because of their mutual trust and friendship (Respondent M9).

In general, family caregivers seem to take over the coordination and organisation of care, help with various small and big practical problems, but only rarely offer help with ADL needs. This is in accordance with the scientific literature. However, the latter also seems to depend on the specific situation. As the literature already points out, partners in general have little shame or shyness to help each other with their hygiene, going to the bathroom, washing, putting on clothes, ... (Respondent S14). Also, one family caregiver used to be a nurse (just like her friend for who she cares) through which both of them feel little to no shame or shyness when she sometimes helps her friend with her personal hygiene (Respondent M9).

In sum, with increasing vulnerabilities and care needs, one or multiple family caregivers gradually take on more and more tasks and coordinate the care around the senior support a senior with his or her care needs. In some instances, the involved family caregivers communicate a lot among themselves in order to organise the care together (Respondent S2, M3, S14). Indeed, one senior has eight children who all agreed to take on what they call ‘a care week’, in which they take care of their father by doing his groceries, taking him to appointments or the church, ... (Respondent M3, S2). Nevertheless, in line with what was stated before, the one child who lives the nearest remains the main contact person and is called in case of an emergency (Respondent M3). For another senior with Parkinson, his wife takes on all the tasks in the household, the coordination of care, ... together with their children and professional aid (Respondent S4). In line with this, the four children of a senior who is in a high state of dementia do their utmost best to organise all the care for their mother so she could stay at home (and not go to a nursing home). Indeed, while one son lives together with his mother and continuously helps her (e.g. with ADL, personal hygiene), the daughter is the organiser and coordinator of the care and puts in place all thinkable sorts of professional home care. Furthermore, she goes a full day a week to her mother to take care of various practical needs such as washing clothes, making soup and cooking for a few days, bringing her mother to appointments, and putting her mother in bad to wash her (Respondent M7).

3.2.3 A family care coordinator and the communication between family caregivers and professionals

In general, we observe that there is often little structural communication between professional caregivers and family caregivers of seniors with care needs, especially when the family caregivers do not organise and coordinate the care. This concurs with previous research (Cès *et al.*, 2016). When the senior (or partner) still organises the care, several respondents state that this is unnecessary because they themselves have the oversight (Respondent S21, M12, M9, S16). Nevertheless, in some instances respondents state that their children would ideally be aware of the formal and informal care they receive (Respondent S17). In this respect, a senior had a stroke while being at home for more than 24 hours. During that time, a professional passed to bring her a meal and did notice that there was something strange, but did not contact the family of that senior. The family caregiver blames this on a lack of responsibility of the professional.

> *‘And that woman said very casually to me: ‘oh, but I saw that, because she was not doing well when I brought those meals. It was like she could no longer talk and she stood there with her cell phone in her hands’. And she simply went down and left. If she had simply called me [...] I would have found her already Friday at noon.’* (Respondent M8).

Although there is often little communication between professionals, volunteers and family caregivers (Respondent S21, M12, S17, M18), this also seems to depend on the organisation of the professional care services and on the vulnerability of the specific senior. Indeed, sometimes professionals do leave notes for the informal caregivers (in the home of the senior) to inform them. In some cases professionals also inform a specific 'informal care coordinator' (who belongs to the same organisation) about a care situation, through which that 'informal care coordinator' subsequently proactively takes contact with the family caregiver to talk about the specific care needs of both senior and family caregiver (Respondent M9). Similar, a cleaning aid called that same family care coordinator to inform her about another specific care situation, through which that coordinator called the family caregiver to talk this through. In this specific Flemish region, this 'family care coordinator' is a new function. Hereby, professionals should give signals to that family care coordinator when they esteem that a situation is difficult or problematic (for either the senior of family caregivers), through which the family care coordinator can take contact the involved actors. For this, it is important that those actors belong to the same organisation (Respondent M8).

Further, the communication between professional and family caregivers also depends on the needs of the senior. When the senior is unable to organise his/her own care, the partner or children often organise the care and are per definition often in contact with the professionals to discuss practical issues (e.g. changes in the structure of the support) (Respondent M6, S14). Also, when the dependency and care needs of the seniors are high, that same family care coordinator can inform the family caregivers that they could ask for a reunion in which all involved actors (professionals, family caregivers, volunteers, general practitioners) are brought together to discuss the care situation. The goal of this reunion is that all actors are aware of the presence of each other so that the care would fit the needs of both the senior and his family caregivers (Respondent M7).

In this respect, one Respondent explains that she would like that the professionals who surround her parents would inform her more regularly about the care situation of her parents. To be in order with the privacy legislation, she thinks that the general practitioner of her parents should at a certain age propose them automatically to sign a document in which they state that the general practitioner can discuss their health and care situation with the family caregivers (e.g. their children).

> *'And I think it is very bad that doctors cannot consult the children to say what was talked about with their parents, because of the privacy legislation. [...] Yes, they [the general practitioners] say: we cannot do that; we must let your parents sign a form for the privacy legislation. Then, I personally think that the doctor should let them sign that on the moment, even when they were only 65 years old. [...] Then you are in your process of family care, because the doctor also sees that there is a need for support. That the doctor would contact the children together with the parents from: 'look, this cannot go on like this'. Me, I was all alone, it was like I was fighting windmills.'* (Respondent M8).

3.3 Seniors' assessment of formal and informal care

Most seniors explain that they are very happy with the support they receive (e.g. nursing aid, cleaning aid) (Respondent S13), and that they have no other care needs (Respondent M12, S4). Hereby, various factors determine the quality of the care from the perspective of the seniors.

3.3.1 The importance to have 'a click' with professionals and personnel changes

Many seniors explain that it is very important to 'have a click' with professionals and volunteers, because it is important to be able to talk and laugh with them (Respondent S16, S17, S13, S19, S11, M5). They often see them as company (Respondent S17) and for one respondent their talks are the most important thing that gives him strength (Respondent S19). Further, another respondent explains how she always leaves the dirty dishes, so they can do them together and have a talk: *'When somebody comes over, I have to be able to talk.'* (Respondent S21). In line with this, one respondent finds it a shame that he cannot talk to his cleaning aid because she does not speak Dutch (Respondent S2). A family caregiver about her mother:

> *'I did notice that our mother saw her [the cleaning aid] more as 'a talk' here in house, and that that woman was not able to clean. [...] I know that she really did her best, but that women could do her work properly during her hours because our mama stopped her [by talking all the time]. [...] She did not do anything here; she entered, and sat here for three and a half hours talking to our mother [...].'* (Respondent M8).

Hence, many respondents explain that it is important for them to personally know the professionals that pass by *'with their pros and cons. So, everything depends on who you receive, can you build on them?'* (Respondent S4). In this respect, it is important to have 'a click' with those professionals because it makes it easier to talk about various subjects (Respondent M5, M9, M7, S13, S16). Furthermore, this click makes it easier to give those 'strangers' access to their private living world (Respondent S13).

Because of this, many respondents find it a shame that their personnel changes every two years because it means that they have to start all over again (to get to know them and to explain what they need to do). As a result, when the care organisation offers a replacement due to unexpected circumstances some respondents refuse that replacement:

> *'I prefer the fixed one. [...] It does not bother me, but you have people that you already know for a long time, you have a connection with them. Then, somebody else comes over, and then you have to explain everything again. I do not find that very pleasant.'* (Respondent S21).

In line with this, some seniors do not want too many professionals in their home because it requires energy from them which is tiring (Respondent S14, S17).

> *'When they do not come a certain week, then I feel like I am on a holiday. Much pressure falls away then. [...] You must take it into account, wake up on time. Yes, that takes up a part of your time.' (Respondent M15).*

Therefore, it is welcomed when the same professionals always help them, and when there is little turnover or changes (Respondent M7).

This is all the more important with people with Parkinson or dementia, according to the family caregivers:

> *'But that [change of personnel] is in a situation with someone who is dement very difficult. Our mother now barely recognises them. So if every three minutes there is someone else.. So we got it done through our general practitioner that they could stay the same.'* (Respondent M7).

3.3.2 Formation and empathy of professionals

Two respondents think that professionals are not always sufficiently formed (Respondent S2, M7). One family caregiver of a senior with dementia explains that although all professionals do their utmost best, many of them do not have the needed experience to deal with people with dementia who still live at home. There is little specialisation in those services: *'They are not trained to deal with her anger, aggression.'* (Respondent M7). Further, another family caregiver finds that some professionals do not have sufficient empathy, involvement and passion for their job through which they do not actively think about what the seniors need. This family caregiver finds that professionals need to feel involved and responsible, which has a positive effect on the relation with the senior and therefore also on the offered care (Respondent M9). This demonstrates that the central empowerment principles remain very important as a way to assess practices and programs, such as having a positive attitude (which is based on equality, respect, presence, encounters and trust), participation of the seniors (having a say and influence), inclusiveness (involvement, integral working method, structure, coordination and a proactive working method (De Witte & Van Regenmortel, 2019a).

3.3.3 Difficulties asking for support from family caregivers

A number of respondents have no difficulties asking their close ones for support (Respondent S14, S4, S19). *'We have no problem with that.'* (Respondent S4). One senior found it evident that her children would take care of her after her husbands' death. She said to them: *'Ah, and from now of on, you will take care of me.'* (Respondent M12). Another respondent also finds it evident and talks about how he also took care of his parents.

> *'I find that normal, that is no bother. That is self-evident. [...] That is out of love, affection, they are no bother, they feel that they are no bother [his parents when he took care of them], and it is important that they feel that.'* (Respondent S14).

In line with this, another respondent indicates that his daughter does the things for him that he can no longer do on his own, and that he has no difficulties to ask her for help (Respondent S19). Another senior family caregiver indicates that she has no difficulties asking her children for help: *'You need to mention it and then they gladly do those things for us.'* (Respondent M15).

Nevertheless, many other respondents do have difficulties asking their confidants for help. *'Yes I find that difficult. Asking others for help, I find that difficult.'* (Respondent S14). This can be explained by several factors. First, a number of respondents have difficulties accepting their own vulnerabilities and limitations. Indeed, many seniors have trouble with the process of becoming more dependent and no longer being able to do certain things (Respondent S13, S2, S21). However, they do realise that it is important to accept those vulnerabilities.

> *'That is less and less. [...] Everything takes much longer. [...] It starts to be a burden. [...] That comes gradually; you do not lose everything from one day to the next. That is ageing, that is learning to let go. And for many people that is difficult and that makes others unhappy if you cannot let go. [...] I deal with that and accept it.'* (Respondent M15).

A senior with Parkinson: *'You must accept that. [...] You should not be unhappy about that; everybody must take a step back at a certain moment.'* (Respondent S4). Nevertheless, they have trouble in this respect, which makes it difficult to ask others for help. A certain respondent does ask her son often to help her out with various small practical issues, but always says she is sorry that she can no longer do it on her own (Respondent M6). And although another senior family caregiver could very much use help with respect to her husband (with care needs), she finds it extremely difficult to ask others to help her and will only ask for help when it is impossible for her to do it on her own.

> *'Saying yourself that you cannot do it I guess. I will still think good about myself I guess, preferring to do it on my own. Until the moment that it is no longer possible: I think that then I will use my mind.'* (Respondent M5).

Second, another respondent explains that he finds it difficult to ask for support because he feels that their relation would then become too one-directional, which bothers him (Respondent S14). Thus, the lack of reciprocity in their social relations can hinder seniors from asking others for help. In this respect, seniors often try to do something back for their family caregivers. One respondent for example asks his grandchildren to mow the lawn, but will always give them some pocket money in return: *'When you have money, to be frank, then that is not a problem.'* (Respondent S4). Third, the quality of the bond with their family members is not always very good, through which they do not dare to appeal on them: *'But I find that is normal, because she [one of her daughters] has another character as her sister.'* (Respondent S11). Fourth, many seniors state that their family caregivers also have a life on their own, through which they try to avoid asking them too often for support (Respondent S10, S14). *'They also have their own chores. [...] When I ask something they do it, but I prefer not to ask them.'* (Respondent S21).

'For the moment I call them as little as possible' because they 'have their own busy lives.' (Respondent S16). *'Yes, they have their own life world.'* (Respondent S2).

In sum, seniors have no problems asking for help when it is really necessary, but they try not to ask too much from their close ones in order to maintain an equilibrium and sufficient reciprocity in their social relations. *'In between I try not to bother them. [...] What I can do myself, I ask from nobody.'* (Respondent S19). *'Yes, but I cannot ask too much help, I know what I can ask.'* (Respondent S11). In this respect, one family caregiver admits that her mother has difficulties asking her for things:

> *'She is a specialist to beat around the bush [laughs]. So I really have to ask her: 'mam, do you need something? Can I do somethings? You want me to do that?' Before she says: "alright, yes that would be good". [...] I think she is scared to bother us too much. But when there is really something, when she has no other choice, she will ask us.'* (Respondent M12).

3.3.4 Flexibility of the senior

It is often difficult for seniors when formal or informal caregivers take over certain practical and care tasks because they themselves would have done those tasks differently. These differences concern the timing and planning (when they come to do certain tasks), how tasks are done (e.g. not cleaning well in the eyes of the senior) and if mistakes are made (e.g. bringing other things from the store than asked or wished). Indeed, many family caregivers will for example help a senior when it fits their own schedule: although some seniors state that they understand this, they do mention that it is not perfect for them (Respondent S2). The same goes for the professional caregivers who do not always come on the exact same hour: although this bothers some respondents, many of them understand: *'But you cannot ask that. They do not know either when somebody is sick and they need to send a replacement.'* (Respondent S16).

Hence, while some seniors are flexible in this respect, others are not. Some respondents (mostly family caregivers but also some seniors) discuss this lack of flexibility.

> *'Then [when professionals come over] I can start to boil in myself. No, that is not possible. I think that.. But it is like that with those people, they want to help, they want to do good.. But it is not always how you want it.'* (Respondent S13).

> *'What I have right now [as a cleaning aid] is terrible. [...] And when I ask her to do it differently, when I ask: 'you should do it like this and this ...' She does not listen.'* (Respondent S17).

A family caregiver states that his mother always wants things done on the short term, and does not sufficiently take into account that other people have a life and family on their own (Respondent M6). Another family caregiver about her senior mother:

> *'Let's say my mother is the stubborn type. [...] She likes to have control. [...] She wanted one sort of milk, but it was no longer available so I bought another type. She was not happy with that; she could not accept that [...]. Since that moment, she no longer asked me. [...] We needed to re-educate her in that respect. But I think that is the case with most seniors: they often think that something must happen, and then it must happen directly.'* (Respondent M12).

This lack of flexibility of some seniors seems to be related to both their character and their shrinking life world through which a small thing in the eyes of the family caregiver seems like a very important thing in the eyes of the senior. Sometimes, they seem take too little into account that their family has a life on their own (Respondent M18, M6).

> *'They [seniors] have only their small life world, so when there is a problem, it must be solved as quickly as possible. [...] That may result in tension. [...]. We have an arrangement: we take a turn to visit her, but in her mind she finds: 'that must be every "x" weeks', and she would prefer to have already in the beginning of the year a calendar of that person comes at that moment, and she comes at that moment. [...] You adapt yourself to it, when she texted recently for example: "my shower broke down". [...] Then I say: "alright, I better go as quickly as possible", because otherwise I will afterwards receive three or four texts from: "you have not forgotten?" But I think that is related to that age. Yes, they have less to think about or worry. [...] Also, when I have some time and I call her, but she is watching her television show at that moment.. [...] It was like: "oh, yes, but it is not possible to call right now. And the phone is dead [laughs]". So, she lives in her own reality. Everything must fit her structure.'* (Respondent M18).

In this respect, this respondent does mention that it has always been like that with his mother, and that it lays within her character (Respondent M18).

A similar story is told by another family caregiver, who explains that his mother finds it difficult to let others do things, through which she interferes all the time, which is not pleasant for him: *'When I do those [practical] things when she is there, I am screwed from the beginning until the end because she does not leave me alone for a second.'* (Respondent M6). In this respect, he also states that this is strongly related to her character and has always been like that:

> *'She finds fixed arrangements important. It was also like that in the past. [...] They [with her husband] went every Tuesday to the GB [a grocery store], not Carrefour, not Delhaize, but the GB. And Tuesday between 11 and 12 am. And at 12.10 pm they were in [a specific restaurant]. Do not try to arrange that differently, because it will not happen. Just to say: that was already like that before. That are things that do not become easier when people get older.'* (Respondent M6).

From these extracts, we find that this flexibility is important because a lack of it can lead to frustration among seniors, and can negatively affect the relation with their family caregivers. Indeed, a certain family caregiver explicitly says that because of her lack of flexibility, the relation between his mother and his family is not good because it makes it difficult to create a good connection (Respondent M18).

Nevertheless, in general most seniors are very satisfied with the (formal and informal) support they receive (Respondent S17) and are flexible with respect to the timing and planning of care (Respondent M9, S19, M20), and find that they do not have the right to complain about those things:

> *'They come to help you and you need to accept what they do for you.' (Respondent S10). 'I admire those women. [...] They rush from here to there. [...] Some of their patients [...] are not satisfied. They would have to be there punctually at a specific hour, and they should do this and that. [...] That it is too much salt or too little pepper in it. Then do it yourself. [...] [When his wife complains that the cleaning lady does not clean properly] I say, close your eyes, close your eyes. Before, people threw sand in the kitchen not to dirty the floor. [...] So one person can adapt better to that than the other.'* (Respondent S14).
>
> *'That is normal [that his daughter does things when it fits her schedule]. I find that normal. You are busy with something, we are two different persons.'* (Respondent S19).

When her daughter brings groceries, she did not ask for: *'Then we eat jam on our sandwich.'* (Respondent S21). One senior finds of himself that he is not a complainer, and that he understands that his family has another life:

> *'I am satisfied because I am not demanding. [...] Yes, of course [he is satisfied with what his children do for him]. When I compare that with my sister, she expects her children to do everything: I do not expect that.'* (Respondent S2). Nevertheless, his daughter is of another opinion: *'Well, he is not flexible. That adjective does not fit him. [...] When you bring something else [from the store], then he will not, he will simply not eat it.'* (Respondent M3).

With respect to how things are done, many respondents are flexible but state at the same time that they try not to continuously verify it because it would lead to frustration (Respondent S21). One respondent for example always goes upstairs when the cleaning aid comes in order not to see how she works, which he thinks is a good strategy (Respondent S2). Another respondent has a similar tactic: he says in short what he expects from the professionals and afterwards let them do how they see fit. Nevertheless, when something is not done right, he will tell them afterwards: *'I let them do as they want and when I see it is well done, good, but if there is a little remark, I tell them.'* (Respondent S19). Further, the same respondent also understands that professionals can be very busy and therefore have little time to talk with him (Respondent S19).

> *'It depends on the person himself. When you are there, and you start to investigate everything very critically, then you could say you are disappointed. But the meaning of life is not to look at everything that way. [...] It is a mixed environment, so you need to adapt a little bit to the whole.'* (Respondent S4).

In this respect, some respondents explain that becoming flexible is a process that takes time:

> *'They all do their best and you must take those people how they come. That is also something you need to learn when you receive help from somebody. If you cannot longer do it yourself, you must accept that somebody else does it differently.'* (Respondent M15).

3.4 The power of giving or a burden of care? A perspective of family caregivers

From the scientific literature, we know that it is not always easy for family caregivers to support a senior in need of care. Not seldom family caregivers are characterised by 'a burden of care'. In this paragraph, first we stand still at the different motivations of family caregivers to offer support. Subsequently, we discuss the degree in which family caregivers experience a burden of care, and stand still at several specific hindrances that make it more difficult for them to provide family care.

3.4.1 Motivation of family caregivers

When we ask family caregivers about their motivation to provide care, most of them find it evident to provide that care. *'That is my mother, so that is normal that I do that.'* (Respondent M12). In this respect, some do not think of this as a clear choice, but explain that it is rather a process they rolled into: *'You roll into it, you do not choose that actually.'* (Respondent M7). Moreover, they explain that it is a process of acceptance to help your close ones with their vulnerabilities (Respondent M15).

First, most children and some partners state that it is their duty to help their close ones, out of reciprocity for all the things they did for them (Respondent M6, M3, M8, M7, M18, M12).

> *'Now, honestly, yes I know it is officially family care, but for me it is no family care. That is just.. my duty as a daughter to do that for my mother.'* (Respondent M12).

> *'I think I can certainly not leave her like that. Those people, I cannot blame them anything, they have been very good to me, I think that I should at least do the same for them'.* (Respondent M6).

> *'Your parents are there to take care of you and then: now it is the other way around, it are your parents who need care. [...] You feel the vulnerability of someone who is alone, who lost his wife [...].'* (Respondent M3).

> *'First of all, because it are my parents and I think you should be there for your parents.'* (Respondent M8).

> *'On the moment she came to be all alone with us, [...] 42 years old, four young children. You should do it. She did it, we all went to college, we all were able to build a future thanks to her character and her being inventive and her perseverance [...] I have something like: we owe her that. [...] She took care of us like that, I think we should do it now.'* (Respondent M7).

> *'The moral duty I guess, towards your parents.'* (Respondent M18).

A partner explains that she does have a choice to provide that care, but:

> *'You choose that man. It is not because he can no longer.. [...] He worked all his life for me, made sure of everything we have now. [...] That is a little bit my duty [...] I am also a catholic. I do not think I will be rewarded for this, but I do think it is not lost neither, when we die, that it has meaning what you do.'* (Respondent M5).

Second, some respondents also state that it is their upbringing and specific character that makes them provide so much care for her parents.

> *'I always had to listen. That was our fathers' rule. Listen, listen, listen. And I got my motivation from that. [...] look, you will never be able to blame me that I left you to your fate. [...] I would never be able to simply leave them to their destiny. That is not in my character, even if that means that I ignore a part of my life.'* (Respondent M8).

> *'I have that towards everybody. [...] I am the caring type. [...] And I think indeed that we owe her that. And as long as we can keep doing it and it is feasible, I will try to keep doing it.'* (Respondent M7).

> *'Yes, he is my father [...] That seems natural to me, it grew automatically. [...] It is also the character I guess.'* (Respondent M20).

Third, some respondents find it evident to offer the care, out of the emotional connection: *'Because you love each other.'* (Respondent M15). Further, another family caregiver offers the care out of a feeling of responsibility, involvement, friendship and the emotional bond (Respondent M9). And last, one family caregiver (together with her siblings) takes care of her mother with dementia, tries to grant the latters' wish never to go to a nursing home (Respondent M7).

However, although most respondents find it normal to offer care, one family caregiver explains that it is possible not to offer (much) family care. Indeed, because of his own family situation, her brother choses to be less involved in the care for their mother (Respondent M7).

3.4.2 Burden of care?

Family caregivers put a lot of time and energy in providing care for their close ones, which depends of course strongly on the care needs and specific situation of the senior. In this respect, we observe that while this can be 'a burden' for some family caregivers, for others it is not.

Some respondents express that it is not a burden to help their close ones (Respondent M12, M6, M20, M3). A retired family caregiver explains that it is not a burden to help his senior mother because he has sufficient time and can easily plan it into his schedule (Respondent M6). Another family caregiver: *'I can also still make my choices and say: that won't be possible right now. So no, I do not feel ...'* (Respondent M20). Further, one family caregiver organised the care for their father together with her seven siblings, by each sibling taking turns every week with respect to the care for their father. This goes very smoothly she says because that way each child only has one week every two months to provide the care of their father. However, before that system:

> *'[...] it was me and my sister who took the biggest part on ourselves, it was heavy actually and sometimes a little bit frustrating towards our other brothers and sisters that they did less. So this solution is very good actually.'* (Respondent M3).

Nevertheless, for several family caregivers it is often 'a burden' to provide care. One partner explains how helping her husband with putting on his clothes, helping him in bed, ... takes a lot of energy.

> *'Yes that asks an effort, physically that is fatiguing, and I do feel that yes. [...] However, physically that becomes heavy, that is an effort. [...] Sometimes I can shout on him.'* (Respondent M15).

Another partner with a husband with Parkinson talks about what she does during a regular day:

> *'When it is a little bit much from time to time, I can scream off course. [...] I can be angry from time to time. [...] The last five years it is taking care of him constantly. [...] It all involves around that, but I also need to cook, take care of the house. [...] Going out, that is no longer possible. Especially the last two years. [...] It increases all the time. The pressure increases. Eight or ten years ago, he was hospitalised a first time: then, I said firmly: 'no, there is no way I will put him away'. In addition, I will try to continue to say so, but maybe not so firmly anymore. When it is no longer possible, it is no longer possible.'* (Respondent M5).

A family caregiver explains how they installed all possible sorts of professional care around her mother with dementia (a sitter, a day care centre, ...), just to give her brother who lives in with her mother some time to breath (Respondent M7). In line with the previous, another family caregiver explains that it was extremely tiring to care for her parents:

> *'She [a social worker] told me: [...] you have a lot of worries, you are too worried and you spoil them all the time. [...] So take it easier on yourself.'* (Respondent M8).

In addition, a family caregiver talks about the difficult situation when her friend was hospitalised and she needed to take care of everything in that period: *'Then, you do everything, and that was difficult.'* (Respondent M9).

Based on our interviews with both seniors and family caregivers, we describe a number of factors that make it difficult to offer durable family care: being constantly available, the emotional burden, social isolation, geographical distance, demonstration of appreciation and reciprocity, the relation between the senior and family caregivers, and incongruences with respect to the care needs of the senior.

3.4.2.1 Being constantly available

A first factor is that family caregivers (mostly the persons of reference) need to be available all the time to deal with practical issues, especially for seniors with high care needs. It is a constant pressure for those family caregivers through which they seldom have a real moment of rest. One partner of a senior with Parkinson:

> *'You always need to be present. [...] What is the most difficult? Making sure that all is in order, that he is a little bit happy. That, all of that. Constant attention. He cannot go alone to the toilet, so 'x'-times a day he calls me. [...] He cannot go to the bedroom alone, or go to bed alone, or get up alone. Every night I have to get up with him, it is all of that. [...] That is difficult. [...] That is the reason he goes to the day centre twice a week.'* (Respondent M5).

A daughter of two parents with dementia:

> *'She called me 12 times between 7 am and 12 am, which is no longer feasible. I do not dare to put my cell phone on "vibration" because I think: what if something happens. [...] I received all the telephone calls from all the institutions because our mama simply forgot. So when the cleaning help could not come, they called me. If there was something with the meal delivery, it was me as well. [...] It was simply: always those telephone calls. [...] That was sometimes a very heavy burden. That your phone is constantly ringing.'* (Respondent M8).

Before, she took both her parents on a holiday for ten days: *'After those ten days I was more tired than when I left, from always having to pay attention.'* (Respondent M8).

3.4.2.2 Emotional burden

Second, family caregivers not only need to be constantly available to solve practical problems, but it is also an enormous emotional burden for them. Indeed, depending on the situation, they constantly worry about their close ones.

> *'And mentally, it is always with you. When I arrived there today, the curtains were closed, the door is not open yet, she is not awake, then you think 'it is possible, you go up the stairs with a small heart because you think that you will find her upstairs, so that is constantly.. [...] That never leaves your head, even when you are at home with your... I have a family, I have grandchildren, but it never leaves. Our mother runs through all of that like a thread. [...] Because you ask yourself: [...] where will this end? Are we continuing to do this?'* (Respondent M7).

Besides worrying constantly, family caregivers are also sometimes confronted with the physical and mental deterioration of their parents or partner through which those seniors change drastically: they may become aggressive, angry with them, ... One family caregiver states that it is emotionally very difficult to care for her mother with dementia because it is one long goodbye.

> *'It is mainly mentally difficult, you see her deteriorate, that is not really your mother anymore. [...] She can also be very angry, especially on me. On the ones she is the closest with, she is the angriest. That is a known phenomenon I think. [...] She no longer washes herself. She no longer wants to take a bath, she does not allow the nurses to wash her, so I now do it every Saturday. And that is a real war to get her into the bathtub. I do it together with the nurses now, because she still listens a little bit to me.'* (Respondent M7).

Even to make her go to a day care centre, a family caregiver always needs to be present because her mother often shows much resistance:

> *'Yes, he [her brother] must make her purse ready and make sure that she gets in that bus, but, 'I do not want to get on that bus', and then she is back inside, puts her purse away, takes of her jacket.. Yes, that is very difficult.'* (Respondent M7).

This respondent explains that her mother always wants to maintain control through which she is often angry when others want to do things for her (Respondent M7).

In line with this, one partner of a senior with Parkinson explains how she finds it very painful to see how other people among which their general practitioner and children no longer talk much to her husband when they come over, because of his illness. *'Yes, he was already done right. What do they need to do with him? [...]'* (Respondent M5).

Another respondent deals with many doubts and is scared when she thinks she would no longer be here, because then both her husband and her son (with a handicap) would be institutionalised:

> *'Must I be honest? I hope that it will not take another ten years. Also for our son [who is handicapped]. Off course, you think about that. If I die first, that two big poor fellows will have to go to an institution. Who would like that? I try not to think too much about that.'* (Respondent M5).

In line with this, a respondent explains that while she and her siblings try to grant the wish of her mother never to go to a nursing home, the care situation becomes extremely difficult for all of them. As a result, she and her siblings deal with feelings of guilt when thinking about sending their mother to a nursing home, which is an enormous emotional burden for her (Respondent M7).

3.4.2.3 Social isolation

Third, some family caregivers explain that they almost never go out, because they would be worried that something would happen to their husbands with severe care needs. However, this is because not only they need to be available all the time for practical issues, but also because they would have emotional difficulties with leaving their husbands while they would have fun (Respondent M5, M15). *'I could not enjoy knowing that he is somewhere ...'* (Respondent M15). In this respect, a senior family caregiver has many feelings of guilt when she thinks about going out, in part because of the many comments of her husband in this respect. As a result, she does not want to go to a day trip with some friends,

> *'Because I think that he would have heart pain [...] when I go away for my pleasure. [...] I do not do that for him. [...] I would not know what his idea would be, if I would go out [...]. Because from the beginning he said: 'it is to get rid of me'. I was not put up with that. [...] That is not pleasant no. 'They drop me there [at a day centre] he says.' [...] Always while laughing but ...'* (Respondent M5).

Further, because of her husbands' vulnerabilities, they no longer do any social activities, through which their social network shrunk drastically over the years and through which she has the feeling that she has no friends left.

> *'Once you are sick for over ten years, nobody looks anymore for you. [...] No more contact, little, very little. You can no longer go along. [...] I would not know with who. I have nobody to do nice things with. [...] Lonely not yet. But isolated yes [...] Nobody passes by anymore.'* (Respondent M5).

3.4.2.4 Geographical distance

A fourth factor which can hinder providing family care is living closely to the senior, because this makes it much easier to take on a prominent role as a family caregiver. Indeed, some respondents live relatively far away through which they cannot simply pass by, which increased the family care burden: *'Yes, that is a great burden.'* (Respondent M7).

3.4.2.5 Demonstration of appreciation and reciprocity

Five, the appreciation by the seniors for the care they receive from their close ones is very important for the latter, which is also found in other research (Institute for the future, August 2020). This is not only important as a sort of recognition for all the things they do for them, but also because it makes the process of care a pleasant (or unpleasant) experience. In this respect, we see that while some family caregivers experience much appreciation, others only experience very little appreciation. And although most seniors indicate being very grateful for all the things their family caregivers do for them (Respondent S2, S17, S11, S17, S14, S19), they do not always *express* their gratitude and show appreciation. This seems to be strongly related to the character of the senior.

In this respect, some family caregivers do feel and know that the seniors appreciate their support, but it is not always pleasant to give that support. A family caregiver explains for example that although she receives enough appreciation from her mother, the latter at the same time finds it very normal to receive all that support. When her mother became more dependent, she said to her: *'Ah, and from now on, you will take care of me.'* (Respondent M12). In line with this, another senior says that he appreciates the support from his daughter:

> *'If I did not have her, I would not know what to do. [...] I appreciate that very much, and she knows it very well. And the others know it. [...] I for example say [name of daughter]: "if I did not have you" ... I say that to her.'* (Respondent S2).

However, his daughters' perspective is that although she knows that he does appreciate, he does not always give her a good feeling when she helps him through which it is not always pleasant to help him:

> *'We all do a lot of effort to bring something [food] from home, but he is a difficult eater. Yes, he is never enthusiast about that. And sometimes you say to yourself: I will no longer bring anything. [...] It is difficult to say because I do know that he appreciates it, but yes.. Being attentive to give us a good feeling, that is not there.'* (Respondent M3).

Another family caregiver explains how his senior mother only talks about the things he does wrong while he is helping her with practical chores. Nevertheless, a few days later she will always tell him that she appreciated him helping her. *'I know that she appreciates those things, she does not need to say those things.'* (Respondent M6). Last, a certain senior says that she appreciates very much that her friends do so many things for her, and that she expresses that to her friends: *'Off course, they know that. I am very grateful for all of that. [...] Thanks to them I can stay in my own home.'* (Respondent S10). However, one of her two friends explains that she seldom receives any appreciation, but that she can nevertheless contextualise it because her friends' character is like that, she has little empathy.

> *'That is because she is always alone, that she has no attention for that, but that she will never say to me: 'here, now I will invite you because you always pass by here with so many things.'* (Respondent M9).

In this respect, on rare occasions, she does receive appreciation:

> *'I was very grateful and surprised. [...] That evening [when she left the hospital], she [her friend] came over with a taxi at 6pm to sleep the first night with me. She slept in that chair over there and I in the relax because I could not go upstairs. [...] That way, I know that when it is really necessary, she does feel it.'* (Respondent M9).

However, some other family caregivers indicate that they do not feel any appreciation from their partner or parent. One family caregiver explains that his mother never did show much appreciation and that there is very little reciprocity in their relation.

> *'She organises it all herself, but taking into account the other party.. [...] With our mother it is mostly one directional. [...] And to be of service to her.'* (Respondent M18).

At a certain moment, she said to him: *'I have taken care of you all of my life, and now you must start taking care of me'. I still remember that, I still get chicken skin.'* (Respondent M18).

As a result, his relation with his mother is not very good which makes him reluctant to help her. Indeed, although he organises the care for her, there are clear boundaries and limits to his support. He explains that he would do much more for his mother in law than for his own mother because

> *'It is mostly the manner in which.. the obligatory character. [...] For our mother I would never do that. Because, [...] it has already been a lot, a lot, a lot of one direction. And because she finds it too much as an evidence that we should just do all of that. You understand? That has to do with appreciation also, with empathy. [...] Most of the time it is like: I will do it [a chore] as quick as possible to no longer have to deal with her nagging, because otherwise she keeps texting. [...] They always say love has to come from both sides, but ...'* (Respondent M18).

Because of this one directional relationship where there is little appreciation, this family caregiver and his family are very reluctant to go visit this senior, and every visit is always functional and practical:

> *'That is then also most of the time the reason to pass by. [...] When there is a practical thing. [...] It no longer happens that way from 'let's go visit her'. [...] That is really a chore to go there. [...] You reap what you sow.'* (Respondent M18).

Further, another respondent also explains how she never got any appreciation from her parents when she did things for them. And although she does her very best to help them, her parents from time to time even complain to her that she does not do enough for them.

> *'My father never told me for example: you did good to solve that for us. I always wanted the best for him, but he always complained. [..] Once he told me: "what do you think? You are not going to tell me what do to". But when there was a problem, my phone always rang. He simply found that normal: "there is a problem and our [name of daughter] will take care of it". [...] That is the most tiring, that resistance and that all of it is normal, and that you regularly get the remark that it is not even good enough and that I did not care enough for my father. [...] But [her mother] said: "but you can do all of that [cleaning their home]". [...] Yes, that was already too much, because than I did not want to do that for them. You see, and then, I again received the feeling that I did not do enough.' (Respondent M8).*

Last, a senior with Parkinson tells us that he finds it *'self-evident'* that his wife helps him with practically everything, because he also helps her with certain things:

> *'I have no problem with that, so I am relaxed and calm in that respect. When there is a problem, she will take care of it. And if she cannot take care of it because it is not in her formation, I can do it. That is no problem at all. [...] Depending on the sort of problem [the both of them cannot solve], I will ask one of my sons.'* (Respondent S4).

Nevertheless, his wife does not see it like that and expresses that she lacks appreciation from her husband (and also from her children):

> *'The appreciation for example, that is worth a lot. [...] He thinks it is self-evident, he thinks it should be like that. [...] He never says that I do good for him. [...] He never explicitly says that, that I take good care of him. [...] Never. But that will be his character I guess. [...] I think that is sad yes, sometimes. [...] With 'family care' they sometimes put you in the spotlight, you see. On the day of 'family care', I receive a card and a telephone call. [...] And that feels good off course. [...] That would be pleasant [receiving appreciation from her husband], but that is not the case.'* (Respondent M5).

3.4.2.6 Relation between senior and family caregivers

Six, the quality of the relationship between senior and family caregiver is important because it has an effect on the way the care is given. In this respect, one family caregiver explains that his mother always 'nags' to him, but never to other people with who she is less close (e.g. professionals).

> *'I think the biggest pleasure she has is to nag. The day she stops nagging, I will start to worry about what is wrong. [...] She talks and mainly wants me to listen. [...] But when that doctor came, it was like if she was a newborn: all the doctor asked, she said that nothing bothered her. [...] And when those people [professionals] ask her something, everything is always in order, it is as simple as that.'* (Respondent M6).

As a result, this family caregiver explains that it is not a pleasure doing things for his mother. He does not simply drop in because she always says him what to do and interferes in his life, which he does not appreciate.

> *'Most of the times, I ask her when she is not at home, and I go do it [practical shores] at that moment. [...] In order to avoid her. [...] When I go to her, she is always saying how I must live my life. But about her, we do not talk. And I am sorry, but I can miss that. I do not need her advice and the only way to avoid that is not to go see her.'* (Respondent M6).

Another respondent also explains how the lack of appreciation from her parents makes her unhappy: *'And in the end, it makes you outrageous.'* (Respondent M8).

Further, most of the respondents say that their relationship did not change because of the care that is offered (Respondent M6, M8, S19, M20, M15, M9, S10, S11, M12, S4, M5, M18). However, this seems to depend on the care situation. One senior feels a little bit warmer towards her son with who she does not have a great relationship: *'I felt a little bit more.. That I thought: that sweet boy I knew is back.'* (Respondent S17). Also, a family caregiver explains how her relationship with her mother changed drastically since the latter became dement.

> *'I no longer visit my mother as a child. I come over and I start organising everything. And that is why she is so angry. [...] A different role. [...] You are in a completely different relation, you are the one who takes care of her, no longer her child that is with her. And she does not see it like that. She still sees us as children who come to visit [...] That results in tension [...] That is difficult, because you do not want to argue with her all the time. I do not come to visit her one full day a week to have arguments all day long. So that is very difficult. [...] Saying to my husband to keep her busy during 10 minutes, so I can put her clothes in the washing machine. [...] So you need to go behind her back, and that is very tiring, and very burdening.'* (Respondent M7).

3.4.2.7 Incongruences with respect to care needs of the seniors

Last, it happens that family caregivers and seniors disagree about which care or support the latter could use. In this respect, we see that family caregivers often insist that seniors to take up more support and that the latter are often less inclined to do so.

Indeed, a family caregiver would prefer that a professional would wash her father because she thinks it is too dangerous that he still takes a bath on his own. Nevertheless, her father does not want to (Respondent M3). Another family caregiver had to insist many times before her father would get his hearing aid fixed: *'Now, I can explain something in three times instead of 20 times [laughs]* (Respondent M20). Next, another daughter wants her mother to ask more support (even if it is just for company) or go to a nursing home to be more safe, but her mother finds it too expensive (Respondent M12). Next, another family caregiver states that she continuously tries to convince her friend to lose weight (Respondent M9), in vain. Another daughter also said *'I had to move heaven and earth'* to let her parents accept some professional aid to come clean their home (Respondent M8). Further, still another family caregiver explains how he had to let a doctor come over when his mother was in pain without telling her, because the latter did not want to see a doctor. She neither wants to move to a more suitable home, an alarm bracelet for when she falls, a hearing aid, that her son puts the heaving liquids on the ground floor (instead of in the basement), going to a day centre, ...

> *'I already begged her for more than six years to buy a hearing aid. [...] So I drive to the store, I stop, she gets out because she did not realise what happened because she was telling a story. She gets out, and I say: now we are going to do a hearing test. And she said: no I do not do that. [...] So everything to make her life more easy, she does not want it.'* (Respondent M6).

3.4.3 Proposed solutions

Based on the interviews, we discern a number of factors that according to various respondents could help to decrease the burden of care: the presence of a family care coordinator, group discussions with other family caregivers, professional services and a multi-disciplinary care discussion.

3.4.3.1 A family care coordinator

A number of respondents who are all supported by the same care organisation in the same region, express their immense gratitude for one specific social worker, a 'family care coordinator' (Respondent M8, M7). The latter is a new function that was created to support family caregivers by taking on the coordination of the family care, proactively searching contact and having discussions with family caregivers to detect their needs and formulate possible solutions for their problems by informing them about various kinds of services.

First, this family care coordinator is very useful according to the family caregivers because of their need for more integrated information about which services and support exist (Respondent M8, M7). In this respect, some of them say that it would be helpful to proactively contact family caregivers and discuss all options when a senior is hospitalised or has to go to a nursing home. This is especially important for people who less easily find their way to available services:

> *'There are perhaps people who do not have that [experience to deal with administrative issues] or who do not have the insight. That they guide them in this respect that would already be a great help for those family caregivers. [...] [That social worker] helped me through all of that and asked everything to all kinds of instances, of which I did not know they existed.'* (Respondent M8).

Some respondents mention that hospitals or general practitioners do not give such information because they often limit themselves to the medical side (Respondent M7, M5).

> *'That is their tests and their medication, and a certificate for medication, but for the rest, how it all works at home, that is not their cup of tea. [...] A general practitioner looks from a different perspective to all of that. They look at the medical side. They will not organise the home care, they do not really know it that well either.'* (Respondent M7).

Second, the family care coordinator can offer a neutral perspective on the care situation. Indeed, this coordinator made clear to a specific family caregiver who continuously helps her parents, that the care she offered was enough and that she had to think about her own care-life balance. *'And also that you can always appeal to somebody like [name from social worker who coordinates family care] who you can call if you simply want to talk.'* (Respondent M8). In this respect, the respondent explains that it is important that the coordinator talks with the seniors as well to make clear to them that they should not ask too much from their family caregivers, so they understand that providing care takes a lot of effort, and that it is important to show some appreciation.

> *'And it could possibly be good that when family care is started, that if those seniors with needs, if they are still fully aware, that they make clear to them: 'your children are there do something for you, but they also have their own life'. [...] It would be good that even when there are no immediate problems that occasionally they verify if all is going well. In addition, that the seniors who should receive help, are better informed that there are instances that can help them, because my parents always thought: "But our [name of daughter] will do all of that". [...] But they did not realise that I also still had to go to work.'* (Respondent M8).

Another family caregiver of a senior with Parkinson explains that she does not have such a coordinator but that she needs somebody with who she could talk to about the care situation and to help her make certain decisions. At the moment, she does not dare to go out without her husband because she would feel bad about it. Therefore, she explains that it would be good if she had someone who would say to her that she could leave her husband more often in a day centre.

> *'That would perhaps be good [...] Yes, if somebody would say: go do it.. But nobody says so. [...] I have to decide that all on my own. [...] To support your ideas a little bit. I now have to decide everything on my own, everything, everything. You need to decide everything alone.'* (Respondent M5).

However, on the other hand, she also mentions:

> *'If it is up to me, everything would remain the same, because I want nothing else. I want to take care of him as long as I am good. That is not too much for me, it is not too much for me.'* (Respondent M5).

From this extract, it is clear that she doubts a lot.

Yet another family caregiver explained how the same family care coordinator helped her and her siblings to get them all in line (with respect to sending their mother to a nursing home or not) and to discuss the care situation together. She is independent and looks at the situation from a different perspective; giving them a push when needed, but without interfering.

> *'In the end, you do not have many people with who you can talk about that. [...] You need somebody who is outside the situation, with who you can talk from time to time. [...] I think that during a care discussion with my brother, she felt that there were some things not right. Therefore, she took herself the initiative to bring us together and, she follows us from the sideline. But you know you can count on her. [...] She worked for a long time with people with dementia. [...] And she understands that. You can appeal to her. She knows in which situation you are and what you are going through. What kind of process that is because, actually dementia is a long drawn-out goodbye.'* (Respondent M7).

3.4.3.2 Group discussions with other experience experts

One respondent sporadically goes to group meetings with other family caregivers of seniors with dementia. After receiving a lecture about a topic that concerns them, they have the possibility to discuss this topic in-group and ask questions. This gives her both emotional and practical support.

> *'You feel supported in the idea: I am not alone, there are also other people who are in a similar situation and who experience even more difficult things. [...] I think the most important is to have people who you can appeal on. [...] It really helps, also that those people.. they know what they are talking about.'* (Respondent M7).

In line with this, another respondent goes to meetings of family caregivers and seniors with care needs, where they do a certain activity together and discuss a certain topic.

> *'I need that a lot. [...] Talking, talking to people, telling them things, receiving ideas about what and how. [...] That is mostly for the social contact..'* (Respondent M5).

3.4.3.3 Professional services

Many family caregivers need various professional services to support them in their task. While one family caregiver who lives with his mother with dementia from time to time appeals to a sitter to get a moment of rest (Respondent M7), another family caregiver makes use of a sitter, a day care centre and meal delivery to give her some time in which she can rest or do certain chores. Although those professional services are very useful, some improvements are possible in the eyes of the family caregivers. Indeed, when one respondents' husband with Parkinson goes to a day centre, he is already back at home at 4 pm, which implies she has to be home to care for him. This is quite early through which it is difficult for her to do group activities, which often take longer (Respondent M5).

With respect to service flats, some respondents do not think that it would much better than their own home because there is already so much support available in the own home environment (Respondent M5). Nevertheless, another respondent indicates that she would love to go to a service flat together with her husband with high care needs, because it becomes too difficult to care for him in their own home.

> *'Sometimes, I think: we would have a luxurious life. [...] There you are free [in the service flat], you have the services that you can appeal on when you want to. [...] You have no more worries about the house. [...] In addition, it is the attention you always need to have. [...] you cannot leave him alone. [...] I think I would do it immediately [moving to a service flat]. [...] I actually never explicitly told him this, what I am saying to you.'* (Respondent M15).

3.4.3.4 Care discussion

One family caregiver of a senior with dementia explained to some professionals that the care situation for her mother was no longer feasible. From that moment, every three months they organised a 'care discussion' with all involved formal and informal actors to enhance the communication and organisation of the care for her mother. This was needed because one nurse could for example no longer wash her mother alone due to her aggression and high state of dementia. Therefore, they made sure that every time that nurse is present, another professional is also present who can give her a hand if needed. During that discussion, those actors also talk about how to deal with certain behaviour in certain situations. Moreover, they can also discuss the pros and cons of going to a nursing home in all openness. Therefore, these discussions are very comforting for family caregivers because they know that the care is well coordinated and organised, that the professionals are well informed and that they can count on them in times of crisis.

> *'I think that it went very well, and I think that it was good for all of us [her siblings]. You really have the feeling that there is a whole team behind you, you see those people with who you normally only have contact with through the phone or email. [...] You know that you can count on them* (Respondent M7).

3.5 The impact of corona on the lives of seniors and their family caregivers

We asked the respondents, both seniors and family caregivers, how they experienced the first few months during which the government took various restrictive measures to deal with the COVID-19 pandemic. In this respect, we observe that the impact of these measures on the quality of life of the respondents differed greatly according to the specific situation: while some respondents speak about a number of negative consequences, others explain that this situation did not create any new needs (Respondent S17) and had a very limited or no impact at all on their quality of life (Respondent S17, S2, S14, M15, S4).

> *'Corona bothered me very little.'* (Respondent S19).

> *'For me it [corona] did not make a difference. I could not go out anyway.'* (Respondent S2).

> *'I am already not well since 2011. Actually, I am already in a lockdown since 2011 [due to health problems]. My lockdown was there already a long time before and simply continued.'* (Respondent S17).

> *'Actually, very little [affected by corona]. I, we were already less mobile.'* (Respondent S14).

> *'For us it did not make a big difference. We did not feel in lockdown, let me put it like that. [...] For us that was not a difficult period. I did not suffer from it. In addition: our situation barely changed [...] because in general we do not go out anymore. [...] I think that I sometimes found it nice to be left alone. [...] There are people who had many difficulties with that, especially young people I think.'* (Respondent M15).

3.5.1 Fear for contamination

Seniors of 80 years and older belong to one of the groups at risk if they are contaminated with the COVID-19 virus, through which all of the respondents indicate being more cautious than before. Nevertheless, while some respondents were quite scared to be contaminated and limited social contacts as much as possible (Respondent M7, S21, S16, S17, M3), others were not scared at all (Respondent S4, M6, S13, S2, S19, S14, M9, S10, S11).

In the one hand, a number of respondents were quite scared and decreased their physical contacts to the minimum. They did not let anyone come in their home in the beginning (Respondent S16, S21).

> *'No, I do not do that [inviting friends]. I do not invite them her, and I do not go there. [...] I prefer that they do not come because I would worry that I would contaminate them, or they would contaminate me.'* (Respondent S16).

> *'I do not want to go outside. [...] I am afraid of the elevator. [...] On the button where I have to be, I take the key of the care and then I push. But you must hold on to the handles, you must open the doors. I can no longer go outside.'* (Respondent S21).

In addition, their children could no longer come in, and had to leave their groceries in front of the door (Respondent S21, S14, S11). And out of scare to be contaminated, one respondent no longer let professionals come over during several weeks (Respondent M3). As a result, some of the seniors no longer went outside (e.g. to the store), or only went outside to make a small walk around their apartment building (Respondent S21). Nevertheless, while multiple respondents indicate that COVID-19 in the beginning made them scared to let professionals come in their home, this is slowly fading away (Respondent S21).

Although the other respondents were also cautious, they nevertheless did let volunteers with their groceries (Respondent S13), family and professionals enter their home (Respondent SM6, S19, S14, M12, S11).

3.5.2 Professional care and volunteers

In this respect, although all respondents restricted their social contacts to a minimum, most of them still accepted professional care to come over (Respondent M7, S16, S19, S17, M9, S11, M12, S4, M18): nursing aid, meal delivery, home care, ... *'That remained the same. I had no difference there.'* (Respondent S10).

Nevertheless, the degree to which professional care continued during the lockdown depends on the specific situation, which concurs with other research (Institute for the Future, August 2020). First, although for some respondents the cleaning aid continued (Respondent S13), in most instances it stopped during several weeks (Respondent S16, S2, S17, S14). However, this was not experienced as a big problem: *'You do not lay awake from that.'* (Respondent M15). Similarly, while for certain respondents the volunteers no longer came over (Respondent M7, S17), in other cases they did continue to come (Respondent S13). In this respect, seniors could sometimes lean on the support of their neighbours, but only for very small tasks such as putting out the garbage: *'She [neighbour] now says with corona that she can put the garbage outside. [...] But that is all; we know nothing of each other.'* (Respondent S21). Next, one respondent explains that the nursing aid no longer came over because they were only allowed to do the urgent patients (Respondent M7), and another senior explains how she could no longer go have a meal in the social organisation where she used to eat every day. *'One big change is that she could no longer go eat at the social organisation.'* (Respondent M12). *'That was bad. [...] [No longer to be able to go eat at the social organisation] and also walking. Walking there, well.. I was happy to walk over there.'* (Respondent S11). Further, for the family caregivers, a senior with Parkinson could no longer go to the day centre during whole this period (Respondent S4), and the group discussions fell away where family caregivers before discussed their care situation (Respondent M7).

With respect to the professional care, some respondents further explain that when the professionals again started to come over or when they themselves could again go to the day centre, it became less pleasant because the obligation to wear a mask and respect social distancing hinders communication (Respondent M5). *'She must be there [in the kitchen], and I must remain here [in the living room]. No, that is no longer pleasant.'* (Respondent S21). This is again a good indication that the talk with the professionals is very important for the respondents.

WijkConnect

Wijkconnect is a (free) online 'neighbour platform' in the Netherlands on which all available services in a municipality are presented and actualised. Neighbours can also use this platform to verify who offers which help, which organisations and projects exist and who offer support in the background of corona. Further, various organisations can present their activities on this platform. In addition, people can consult the actual news in their neighbourhood or municipality on a news function.

Sociaalwerk Nederland, https://www.sociaalwerknederland.nl/thema/goede-voorbeelden-interviews/nieuws/7812-interview-met-berny-de-vries-gratis-online-buurtplatform-voor-wie-wil-helpen-in-tijden-van-corona, 13 October 2020.

A central hotline home care

In the Netherlands, an organisation created a central hotline that people can contact in order to notify policy makers about the problems community-dwelling seniors are confronted with in times of corona, in order to improve the (home care) policy for those seniors.

KBO-PCOB, https://www.kbo-pcob.nl/meldpunt-thuiszorg/, 13 October 2020.

Practical support by online platforms & neighbourhood support

Many online platforms exist that can be used by seniors with care needs, also in times of corona: helper, give a day, hoplr, local Facebook pages of the own municipality or neighbourhood, ... Indeed, all these platforms try to align various offers and demand. Further, neighbours can also hang posters on their window in which they state that people in need can contact them to help with certain issues. Further, in many instances people are urged to in the mailbox of older neighbours to let them know that you can provide practical support (e.g. doing groceries).

Vonk3, https://www.vonk3.be/uploads/2/3/9/2/23924438/handleiding_tips_en_goede_praktijken_buurtgerichte_zorg_-_versie_20_april.pdf, 13 October 2020; https://www.poperinge.be/burenhulp, 13 October 2020.

One central phone number for each municipality

In a specific municipality in the Netherlands a number of social work organisations created one central phone number for vulnerable citizens, where the latter can talk to for (1) a simple conversation or for (2) information about their care needs and available services. The goal of this initiative is to make sure all citizens know which services they can appeal to. For example: Who can do my groceries? Where can I get an affordable meal now the social restaurant in my neighbourhood is closed? In this respect, it is very important that this number is made known by the large public.

Ocan, https://www.ocan.nl/samenleving/actualiteiten/persbericht-gemeente-den-haag-coronavirus-COVID-19-1-centraal-telefoonnummer-voor-kwetsbare-hagenaars, 13 October 2020.

3.5.3 Family care

The impact of the COVID-19 restrictions on the lives of family caregivers seems to depend strongly on the degree of care the seniors need. On the one hand, for some of the family caregivers corona did not make their role more difficult (Respondent M15): *'That was never a burden: for me, towards my mother.. Corona was not a problem.'* (Respondent M12).

However, on the other hand, many family caregivers of seniors with high care needs did in fact experience more burden in this period because they had to take on various tasks that normally are done by professionals or other family caregivers who live further (Respondent M3, S21). Indeed, the respite care fell away (day centre) for a certain senior with dementia, through which the family caregiver who lives with this senior no longer had any moments on which he could rest, which made this an extremely difficult period for him (Respondent M7). In line with this, the wife of a senior with Parkinson who was no longer able to go to a day centre or appeal to a sitter:

> *'Yes, we experienced that, that is heavier. [...] He no longer left, the children no longer came over. Nobody could enter the home. [...] I could no longer leave, even not to go to the store. That was still possible when he still went to the day centre. [...] Absolutely, that is a big difference. [...] That was bad for everybody.'* (Respondent M5).

But although several respondents indicate that this was a very difficult period because some crucial aid fell away, they state that they can think of no ways which could have made that period less difficult for them (Respondent M5).

A telephone line for family caregivers

Family caregivers can call a certain number, where they can talk to specially formed volunteers who take the time to listen.

http://www.samana-antwerpen.be/images/downloads/1504Nieuwsbrief.pdf, 13 October 2020.

Family care coordinator

In a certain municipality in Flanders, a new function is created, namely the family care coordinator. This person gives advice, information and guidance to family caregivers on the financial, social and psychological domain, and concerning all available services for both senior and family caregivers. Further, family caregivers can simply tell their story to that coordinator and also receive sporadically formations and information sessions.

Thuiszorg Leuven, https://www.zorgleuven.be/mantelzorg, 13 October 2020.

3.5.4 Social relations and feelings of loneliness

Because of the restrictive measures of the government to deal with the pandemic, many seniors and family caregivers' physical social contacts with professionals, family, friends and acquaintances decreased significantly. Indeed, other research also indicates that the contact with friends and family is the thing seniors missed the most during this period. Family caregivers are also confronted with this since they also often belong to a vulnerable group (Institute for the future, August 2020). The effect of these decreasing social contacts on the quality of lives of the seniors and feelings of loneliness seems to depend strongly on their specific situation.

On the one hand, some respondents indicate that this period was not especially difficult in this respect. According to one family caregiver, this period had no significant effect at all on the life of her mother with dementia (who lives in with her son). Although her mother could no longer go to the day centre and some of her children were no longer able to visit, she lived together with one of her sons, professionals kept passing by, and another son also visited her every week. Moreover, according to her daughter, she did not realise what took place. *'She did not realise that she did not see us for two months for example. So, for her, I think actually that it did not have any impact.'* (Respondent M7). In line with this, a senior couple explains that although they did see much less people in that period, that this was not a problem because they were still well surrounded by family and friends, with who they talked more often on the phone (Respondent S14, M15). The fact that they were a couple also meant they were not alone in that period. Further, although some respondents were no longer able to volunteer in that period, they indicate that other forms of contact with friends and family increased, such as video calls and grandchildren coming over to waive at their window (Respondent S21, M5). Nevertheless, some seniors are not open or able to face time (Respondent M7, M6).

On the other hand, many seniors did experience the negative effects of corona on their social lives (Respondent S16, M6, M3). In this respect, the respondents first explain that they received much less visits from friends and family (Respondent S4, S16, S10, S17, S13), and that when people passed by it was not like before because they stayed less long (Respondent S16). Also, although some respondents did have more contact with their close ones through the phone or family passed by more often to wave at the window, they missed seeing and talking to people in real live (Respondent M9, S17, M18, M12). *'I missed that off course, yes the fact that I was here alone. But for the rest.. [...] Just the talk, and the company.'* (Respondent S10). *'In the beginning of the lockdown it was bad for a while. Then, nobody came: not the hairdresser, not the pedicure, not the company lady. Only the groceries and that I did through the window.'* (Respondent S17). Second, several respondents also explained how they themselves went less often outside. Indeed, one respondent could no longer accompany his children to the store, go to church, go for a drink with family or friends, ... (Respondent M3). Next, another respondent needs her volunteer to go outside (because she is scared to fall), but could no longer appeal to that volunteer during the lockdown, through which she only left her home twice in three months (Respondent S13). In line with this a respondent who lives very socially isolated, was no longer able to go to the bar she usually went to every day to drink a coffee. As a result, she had almost no social contacts in that period, except for with her son. However, although her son did pass by more often, this was a difficult period for this senior (Respondent M6). Similar, another respondent with very little social contacts used to eat in a social organisation every day where she meets people and which she finds very pleasant. However, during the lockdown she could no longer go there, through which she saw much less people and watched television all day long. She really missed that social contact (Respondent S11). Her daughter:

> *'Even if we passed by every day, she would still have missed it [eating in that social organisation]. I am convinced of that: that is just, not the fact that she eats there, but just that she eats with other people. That she does not have to eat alone, that there are others, that is cosier, more pleasant. People of her age, who lived the same things as she.'* (Respondent M12).

When we specifically ask the respondents about feelings of loneliness, we see that despite that fact that the social contact decreased for most respondents, not all of them felt lonelier in that period. Indeed, some respondents explained that this has almost no impact on their feelings of loneliness (Respondent M7, S4, S21, M15, S19, S13). *'I can imagine that some people [...] feel lonely. [...] For us, that is not the case.'* (Respondent S4). However, many other respondents did feel lonelier because of the decreased social contact (Respondent S16, M6, M5, S21).

> *'I am lonelier now, that is for sure. [...] [The impact of corona] is negative of course. You are alone all day long. [...] Before, when there was no corona, I received much more visit: they would regularly come to get me to spend the afternoon with them. That is no longer possible. [...] Then, a day takes much longer. [...] But that will be the case for everybody.'* (Respondent S16*)*.

Another respondent clearly missed the company of her family, who no longer passed by:

> *'Yes, that hurts. [...] You feel like.. first of all to give them a kiss when you see them. [...] My grandchildren became two years, and I did not see them anymore. And I miss that.' (Respondent S11). 'The first few weeks I did not see anybody. [...] And I found that horrible.'* (Respondent S17).

And a family caregiver about his mother:

> *'That must have been very lonely for her. [...] She suffered from that. She suffered a lot. [...] Then, she talked about loneliness [...] because I was not physically present. [...] How happy she was the first time I could go visit her again: yes, that was great. I was surprised of that impact. [...] She said at that moment: 'Only now I know what loneliness is.'* (Respondent M9).

In line with this, a family caregiver explained that the situation of her mother in law was horrible because she was 'locked up' in her service flat during that whole period. That senior in general does not hear well through which social contact before was already difficult.

> *'That were serious dramas. [...] They were all alone over there for eight, nine weeks. [...] You noticed that: she called 20 times a week. [...] That loneliness yes, that was horrible for those people. [...] That became worse every week. Those stories on the telephone that you thought.. she is not doing well. That is normally broken by visits, by people who pass by [...] Suddenly no longer seeing your children, nobody comes to visit, having nothing. The little she had fell away. She sat there for days. [...] No contact. [...] I think that she did realise the whole corona thing but I do not think that she laid awake from: 'I will be contaminated or I will die from corona'. I think it was more: I am here two months all alone.'* (Respondent M7).

Further, another family caregiver who has a parent in a nursing home:

> *'I know they try to protect those people in the nursing homes but they should do something so all those people could have more contact with their family. [...] Because I asked the nurse [...]: "Did you have many deaths because of Corona?" Yes, she said, "five people passed away on our floor. But I think that more people died from loneliness than from corona". [...] They made such a big thing about: "oh the nursing homes and we need to protect those people". But they did not think about how other seniors who still lived alone suffered from loneliness.'* (Respondent M8).

Buurtpensioen

The ‘BuurtPensioen’ is a local network of neighbours who support each other in their daily lives, according to their own possibilities. Hereby, reciprocity and solidarity are seen as important principles because they give people a place in society and give meaning to life. This program was created in 2013 in Brussels, based on the belief that people could be strengthened by creating more social bonds and connections. By helping each other and being together, (older) persons increasingly take initiatives which results in a dynamic social network that alleviates social isolation. The goal of this program is to alleviate social isolation and loneliness, by helping each other and making each other more resilient.

During corona, the Buurtpensioen indicates that seniors can appeal on them if they feel lonely and want to talk to someone or if they need some help with their groceries. Further, they also appeal to volunteers who want to support their neighbours by doing their groceries or having a simple chat with them.

Het Buurtpensioen,
https://www.kenniscentrumwwz.be/buurtpensioen, 22 October 2020.

Virtual Hugs

Virtual hugs is an initiative that aims to offer tablets and smartphones to seniors and patients in hospitals and nursing homes during the corona crisis, in order to increase their possibilities for social contact and to alleviate feelings of loneliness.

This initiative collects already used technologies and make them ready for use (e.g. by already installing certain software), but they also collect money through an online platform from donors in order to buy more smartphones and tablets. Further, they also provide a manual with Q&A for the users.

De Knack,
https://www.knack.be/nieuws/belgie/coronavirus-solidariteitsactie-virtual-hugs-schenkt-tablets-en-smartphones-aan-ouderen-en-patienten/article-belga-1585607.html, 13 October 2020.

Telefoon*ster*****

This initiative in a certain municipality in Flanders also aims to tackle social isolation among seniors and to alleviate feelings of loneliness.

This organisation collaborates with their municipality, and calls the seniors in their neighbourhood to (1) simply have a chat with them, and also to (2) demand how they feel and if they have specific needs. When they deduct that there are very urgent questions they pass this information through to a specialised service who will subsequently contact that senior.

Gemeente Mol,
https://www.gemeentemol.be/nieuwsdetail/10921/seniorenraad-lanceert-initiatief-telefoonster-tegen-corona, 13 October 2020.

Geen Belet!

Various organisations leaned on volunteers to call already more than 100,000 people, of which many older seniors to detect possible needs, under the name ‘Geen Belet’. In that respect, they asked them if they are doing fine and if they need some help.

Vlaamse Ouderenraad,
https://www.vlaamse-ouderenraad.be/actualiteit/vrijwilligerswerk-verenigingsleven/geen-belet-ouderenverenigingen-belden-al-meer-dan, 13 October 2020.

A neighbourhood garden

In Antwerp, several social work organisations try to enhance social cohesion and social relations between people in a specific neighbourhood (during corona) by inviting them in a public garden to garden together, learn Dutch, or simply to have a drink together.

Samenlevingsopbouw,
https://samenlevingsopbouw-antwerpenstad.be/wat-doen-we/activiteit/samentuinen/, 13 October 2020.

3.5.5 Social and cognitive decline

Last, one respondent explains that because she almost never went out anymore and did not meet any people, she took less care of herself, her appearance, her body, her clothes, ... *'Before, I was prrouder of myself. [...] Yes, now I stay at home, on my couch, sleeping, then you do not need a beautiful dress no?.'* (Respondent S11). In this respect, her daughter also states that her mother worried all the time about her family during the lockdown, and meticulously followed the news (Respondent M12). In line with this, another respondent explains that she thinks that her mother with Alzheimer deteriorated enormously during the eight weeks of quarantine (Respondent M7).

3.6 The key to a happy life

At the end of each interview, we asked the seniors of 80 years and older what gives them energy in life, and what the key is for a happy life.

In this respect, many seniors first mention their social relations with family and friends (Respondent S16, S13, M5, M3, S19, S21), but also with professionals (Respondent S19).

> *'That they think of me, that they call me. That I have friends who pass by. That makes me happy.'* (Respondent S16).

> *'What I find important? That are my children, my grandchildren and my cat.'* (Respondent S21).

> *'Friendly people off course. Just, for me that is all. [...] Always again the social contacts. [...] That is the most important thing.'* (Respondent M5).

Hereby, many seniors explain that reciprocity is crucial in social relations, and they mention that they always try to do things for other people (Respondent S13, M20, S21, S16), such as inviting friends and family to come over to eat, letting them use their apartment at the sea during weekends and holidays, giving birthday presents, volunteering for people with a handicap, ... (Respondent S14, M15). A certain respondent mentions also that caring for others and volunteering gives him a good feeling and something to do (Respondent M9, S14). Another senior agrees and mentions as a tip for a happy life: *'Try to give pleasure to others [...] and you will get it back.'* (Respondent S14).

Further, the seniors also explain that happiness comes from having many interests, activities and goals such as reading, listening to music, watching television, writing a book, gardening, cooking, practical chores, painting, working, ... (Respondent S2, S13, M9, S19, S14). Indeed, this not only helps to deal with feelings of loneliness because it gives people something to do (Respondent M9), but it also makes people proud of themselves, which seems to have a positive effect on their self-esteem:

> *'I have always been someone who is busy. [...] When I tell you of all the things I realised.. [...] That gives me joy. [...] That was like therapy for me, it eases my nerves, and I always kept doing that. When I am busy, I am happy.'* (Respondent S19).

> *'I have had a beautiful life. I always loved to work. [...] I always did many things, and I am happy that I did all of that. [...] I lived how I wanted to live. [...] Advice? To do many things. I have never had the time to complain.'* (Respondent S16).

In this respect, the respondents also mention that it is important to have small or big goals, even when it is difficult to realise them, such as going to the hairdresser alone (Respondent S2), doing the household (Respondent M6, S11, S14), or taking care of a child with a handicap.

> *'Yes, that is her life goal on this moment that keeps her busy. [...] That obligates her to stay.'* (Respondent M18).

Third, many respondents state that it is important to be flexible in life, to be able to bounce back in the face of adversity (~ resilience). In line with this, some respondents also mention that it is important to be able to relativise (Respondent S14) and accept their own vulnerabilities: *'What you can no longer do, you need to let go.'* (Respondent M15). In this respect, they mention that this ability might come from their character and education (Respondent S17, M9, S21, S14, M15):

> *'I am an optimistic person from character. [...] Taking life as it is, as positive as possible. And when there are negative things, accepting them.'* (Respondent S10).

Last, for some respondents their faith is also an important factor for their happiness, just like the ability to enjoy the small things in life: *'That you are happy with your situation on a given moment.'* (Respondent S4, S14, M15, S16).

> *'A man must be happy in his life. That is all that counts. [...] But you must try to be happy: if you are complaining all the time, then you cannot be happy.'* (Respondent S16).

3.7 Conclusion

Based on our research results, we first find that seniors are confronted with various difficulties, which have a strong impact on the quality of their lives. In this respect, first, many seniors are confronted with important health limitations (difficulties walking, hearing or seeing) which hinder them from doing all kinds of activities, sustaining social relations and organising their own care. As a result their dependency of others increases, which is emotionally very difficult to accept. Moreover, these limitations are affected by the bad state of the sidewalks, the impossibility of seniors with a walker or wheelchair to use public transportation, and financial means that could alleviate various limitations by being able to buy various material aids. Further, a neighbourhood where much people live together, where there is much 'life' is positive in this respect, just like having a big home with a garden. Indeed, the life world of many seniors involves their immediate surrounding, namely their home and neighbourhood. Because of these limitations, many seniors find it difficult to remain in their own home, but nevertheless would do anything not to go to a nursing home because of the bad image they have of these places. Second, the death of a partner has detrimental effects because seniors not only emotionally need to get over this loss, but also need to fill in their lives on their own again and make every small or big decision on their own again. Third, many seniors only have contact with a limited number of people and are sometimes confronted with feelings of loneliness. These feelings can be the result of the death of a partner through which they feel emotionally lonely and miss affection, but at the same time sometimes not want to create new social bonds nor have pleasure without their partner. In addition, many seniors feel (socially) lonely due to the passing away of many friends and family members, through which they miss an adequate, broad social network. In line with this loneliness can also be due to the neighbourhood where people live (if there is nothing to do or see in proximity), if their network lives nearby, if their physical health limitations limit their possibilities to go out and sustain social contacts, the character of people which allows them to easily create social bonds. To alleviate these feelings, the respondents emphasise that it is important to still have a partner, to have at least one good social contact, and to have a social network that lives nearby. Also, the talk they have with professionals is helpful in this respect, through which many respondents organise the care so that the presence of those professionals is spread in time. Further, the knowledge and availability of technological communication manners is important, and certainly also having sufficient activities because they keep seniors busy and serve as a distraction, and give them a general good feeling about themselves.

In order to respond to their physical and mental health needs and feelings of loneliness, many respondents appeal to professional care, volunteers and family caregivers. This is often a long-term process that slowly comes together, together with their increasing care needs. At first seniors organise and coordinate that support themselves, and gradually - with their increasing care needs and vulnerabilities - leave this to their family caregivers with who they are the closest and who live nearest. In this respect, professionals in general provide the heavier tasks (e.g. cleaning, nursing aid) and volunteers do the lighter tasks (e.g. doing groceries, accompanying them outside). Hereby, the family caregivers' role often seems to shift from being mainly the partner/child to becoming the care coordinator and the person of reference. Indeed, they gradually take over certain tasks such as the administration and finances, then also the organisation and coordination of care, and ultimately often stand in for a wide range of (small and big) practical needs. Because of the latter, they are constantly available and seniors clearly express that it is extremely important for them to have at least one person on who they at all times can count for practical issues. With respect to the communication between family caregivers and professionals, we observe that this is not deemed needed as long as the seniors themselves organise the care (because then they have the oversight). Nevertheless, when the care needs of the seniors are high, it seems important that some kind of communication is possible between all actors in order to notify each other of possible needs or problems. Besides organising reunions with all involved actors to talk a care situation over, it also seems better that all professionals and volunteers belong to the same organisation (e.g. nursing aid, cleaning aid, volunteers, ...) so that they can easily pass through certain messages, ideally to a family care coordinator who has the task of detecting problems in the family care situation and offering solutions.

From the perspective of the seniors, we find that they are in general very satisfied with both the formal and informal care they receive. In this respect, we first observe that they find it important to have 'a click', a good connection with the professionals and volunteers that pass by because they very much appreciate their conversations and general company. Therefore, they find it a shame that professionals change every two years (although understanding the reasoning for this). Moreover, due to personnel changes they need to explain again what they expect of those new professionals, which requires energy. This connection is all the more important for seniors with severe health issues such as dementia or Parkinson. In this respect, some family caregivers mention that it is very important that professionals are sufficiently formed to deal with those specific situations (e.g. a senior with dementia who is aggressive). Second, while some seniors have no difficulties asking their close ones for support, many others do have difficulties in this respect. Hereby, most respondents always look for an equilibrium try not to ask too much support. The latter can be explained by them having a bad bond with their family, difficulties with accepting their own vulnerabilities, being afraid that their relation becomes quite one-directional, and because they realise that their family and friends have a life on their own. Third, it is important that seniors are somewhat flexible with respect to the care they receive (e.g. what is done, when it is done, how it is done, if mistakes are made). Indeed, when other people take over certain tasks, they will never do it in the exact same way. Therefore, seniors should (learn to) be sufficiently flexible and accept this. This is not always easy: some family caregivers indicate that because the life world of the seniors shrinks, small things can appear to be huge things in their eyes. Nevertheless, the seniors should try to be flexible, because otherwise they could become frustrated and 'nag' to the people that help them, which can lead to a bad relationship and which makes the process of (professional or family) care an unpleasant experience for all actors. In this respect, the seniors explain how becoming flexible is a process which can be learned, but also depends on the specific character of the senior.

From the perspective of the family caregivers, we find that family caregivers - similarly to seniors - explain that this is a process they 'roll into'. And although they all find it evident to provide family care because of feelings of responsibility, reciprocity, the emotional connection, involvement and friendship, several of them are nevertheless strongly affected by 'a burden of care'. The latter seems to depend strongly on the specific situation such as the care needs of the senior, the availability of time of the family caregiver, and the degree to which the care is shared with professionals or other family caregivers. In this respect, various factors clearly lead to a higher burden of care. Indeed, some family caregivers indicate that they always have to be available for the senior, which results in a constant pressure, having no time to rest and worrying constantly. Further, they are also confronted with an emotional burden because they sometimes see their close ones deteriorate physically and mentally, and witness that others (e.g. children, general practitioners) treat their loved ones differently as a result (e.g. not talking to them), which is painful to see. In addition, they not seldom deal with feelings of guilt when thinking about sending their close ones to a residential facility for elderly people. Further, some partners of seniors with need only seldom go outside and see their social network decrease because they want to be constantly available for their partner and because they would feel guilty if they would go out and have fun without them. In this respect, it is important that their social network lives nearby, so they can come in quite easily. Further, although all seniors appreciate the support they receive very much, many of them do not express their gratitude very often according to the family caregivers. Nevertheless, this is very important for family caregivers because of the recognition of all the support they provide and because it makes the care situation a pleasant (or unpleasant) experience. Indeed, when seniors find the support they receive normal, 'nag' a lot and talk continuously about the things that go wrong, this does not result in a good feeling for the family caregivers, nor in a good relation with them. Nevertheless, the quality of the relation is important so that the family caregivers would offer support with pleasure. In this respect, except for family caregivers of seniors with dementia, the respondents did not think their relationship changed because of the care. In order to decrease the burden of care, family caregivers first mention the presence of a family care coordinator, who proactively detects difficult family care situations and contacts those family care gives to talk about their needs, and subsequently proposes solutions for their problems. Indeed, they give integrated information about all kinds of topics concerning which professional services exist, available financial possibilities, and ethical issues. They also offer a neutral perspective and help family caregivers making certain decisions, talk about feelings of guilt (e.g. due to possibly sending a senior to a residential facility for elderly people, or using respite care), help putting several family caregivers on one line, and help making clear to the senior that there are also limits to family care. Other factors that decrease the burden of care are group meetings with other family caregivers which give emotional and practical support, and the 'care discussion' in which all involved actors around a senior come together to discuss the care situation in order to make sure all needs are fulfilled and that the care is well coordinated.

From the interviews, we observe that the impact of the restrictive measures to deal with corona differs greatly according to the specific situation: while some seniors mention several negative consequences, others explain that this situation had a very limited or no impact at all on their quality of life. In this respect, we first find that although little seniors were extremely scared to be contaminated, all of them were more cautious: they went out less often or no longer at all and limited their social contacts as much as possible with both professionals and family and friends. Some of them refused the support of professionals in the beginning, but most of them still allowed professionals to come over. Further, in some instances professional services themselves stopped their activities for several weeks: this was mostly the case for cleaning aid, but also various group discussions (for family caregivers) and the day centres. The latter was not only a severe problem for lonely seniors for which the day centre is an important way to meet people, but also for various family caregivers to have a moment to rest and do other things. Moreover, the seniors explain that the contacts with both professionals and family are less pleasant because the communication is hindered by new rules (e.g. wearing a mask, cleaning in one room while the senior is in the other room). With respect to the family care, we again see that the impact of the measures depend on the specific situation: while some family caregivers mention that this did not change much, others had to take over many tasks that before were done by professionals and family caregivers that live further away, and could no longer rest for a moment because day centres were closed and sitters unavailable. Last, for all seniors the number of physical contacts decreased significantly: one person only went outside twice in a period of three months and other people were no longer able to go to a day centre, a social restaurant or a bar, through which they were all alone every day. Further, the contacts also changed: they were less long, people no longer came into the home, people wore masks, ... However, for some respondents this did not have a significant impact on their quality of life because they were in couple, were in a high state of dementia and did not realise what happened, or because other forms of contact increased. Nevertheless, many others did express that they clearly felt lonelier, which according to some respondents might have been the most difficult for people who lived in service flats.

Last, the seniors explain what for them the key to a happy life is. In this respect, most of them first mention the importance of social relations with family and friends and professionals. Hereby, they explain that reciprocity in relations is of paramount importance, and that caring for others and doings things for others (e.g. volunteering) is also of crucial importance. Besides, social relations, they also mention that it is important to have many activities and interests because it gives people a feeling of pride, self-esteem and simply something to do. Last, they also explain that their faith is important, just like various character traits such as being flexible and resilient, and being able to enjoy small things in life.

4 | Conclusion and recommendations

When people grow older, they are increasingly confronted with vulnerabilities on various life domains, which greatly affect the quality of their lives. Besides the fact that many older seniors are confronted with the passing away of their partner, friends and family, they also have more and more physical and mental health limitations through which their dependency of other people increases. In addition, seniors in Belgium often do not live in an adapted residence in a 'caring neighbourhood', where there are many services and shops in proximity and where it is easier to sustain a social network. This is problematic because the life world of older seniors increasingly involves around the own home and neighbourhood. And although our interviews show that social relations and having sufficient activities form the key for a happy life, research shows that seniors in general participate less to society and that many seniors are confronted with feelings of loneliness. Therefore, it is crucial to stimulate seniors to participate socially and to sustain their social network.

In this respect, from our interviews we learn that various structural barriers continue to impede older seniors from participating to society and sustaining a social network: difficulties going out because sidewalks are not adapted (to walkers or wheelchairs), difficulties taking public transportation, a lack of affordable individual transportation, ... In this respect, stimulating new (technological) ways of communication among seniors could have a positive effect on their social network. Further, we find that besides certain character traits that make it more difficult to sustain a social network, seniors are sometimes also psychologically restrained to form new connections because they have the feeling they should not have pleasure after the passing away of their partner or while their partner with severe health issues remains at home. For those seniors, individual psychological support or group meetings with other seniors could help them reflect on these topics, which could have a positive effect on their wellbeing. And since many seniors do not live in an adapted residence in a 'caring neighbourhood', it seems appropriate to stimulate seniors to 'move in time' to an adapted residence in a neighbourhood in which it is easier to sustain social relations and to participate to society.

Concerning formal and informal care, our interviews show that most seniors are in general very satisfied with the care and support they receive. Hereby, organising the care appears to be a process that slowly comes together and in which both seniors and family caregivers 'roll into'. In general, seniors coordinate and organise the care themselves, but in time and with increasing vulnerabilities family caregivers gradually take over their administration and finances, the organisation and coordination of care, and often also become 'the person of reference' seniors can lean on at any time when they have (small or big) practical needs. Hereby, the seniors state that it is extremely important for them to have at least one such person on who they can count at any time. Next, although some seniors have no difficulties asking for support from their close ones, others do find this difficult for various reasons: they realise their close ones have a life on their own, the relationship would become too one-directional, they simply do not have a very good bond with their close ones, or because they have difficulties accepting their own vulnerabilities which makes it harder to ask for help. As a result, most seniors try not to ask too much of the family caregivers and try to look for an equilibrium. With respect to the professional care, our interviews show that for most seniors it is very important to have 'a click' with the professionals because they appreciate their conversations and general company very much. Therefore, they for example often organise the care so that they regularly see the professionals, and (although understanding its reasoning) several respondents find it a shame that professionals need to change every two years, because this means that they need to reconstruct such a relation with somebody else every two years. For seniors with high care needs (e.g. with dementia or Parkinson) this continuity is all the more important, just like it is important that professionals are sufficiently formed to deal with those situations (e.g. seniors with aggression due to their dementia). From the interviews, we further deduct that it is important for seniors with high care needs that there is sufficient communication between both professionals and family caregivers in order to notify each other of possible problems and to make sure the needs of both seniors and family caregivers are met. In this respect, it seems easier to share information when all professionals (and volunteers) belong to the same organisation, and when there is a specific family care coordinator present whose task is to detect problems in family care situations and subsequently offering solutions.

From the perspective of the family caregivers, we find that while they all find it self-evident to provide that care, some of them are nevertheless confronted with a severe 'burden of care'. This burden not only comes from a constant pressure to always be available for the senior, but also from emotional difficulties when they see the senior (physically and/or mentally) deteriorate or when weighing the pros and cons of sending the senior to a residential facility for elderly people (which is not seldom accompanied by feelings of guilt). Further, family caregivers of their senior partner are sometimes confronted with social isolation because they feel that they always need to be available and that it would not be justified if they would go out and have fun without their close ones. Further, while the seniors say that they appreciate the support from the family caregivers very much, many of the latter find that the seniors seldom show their gratitude or appreciation. Nevertheless, this demonstration of appreciation is very important for family caregivers as a recognition of all the support they provide, and because it makes the process of care a pleasant happening. In line with this, it is very important that seniors and family caregivers have a good relation, which is built on reciprocity. From the interviews, we detect various ways to lower the burden of care. First, family caregivers would benefit from the presence of a 'family care coordinator', a reference person they can talk to about all kinds of practical, ethical and emotional questions. Indeed, by offering a more neutral perspective on their situation, that family care coordinator can help them making certain decisions. Second, the burden of care can also be decreased by stimulating family caregivers to participate to group meetings with other family caregivers, which gives both emotional and practical support. Third, family caregivers of seniors with high care needs also benefit from multidisciplinary discussions, in which the care situation is talked over with all involved actors and the care is organised around the specific needs of both the senior and the family caregivers. Last, both seniors and family caregivers would benefit from a better understanding of each other's perspectives on the care situation, for example through formations and groups discussions. Indeed, on the one hand seniors have sometimes difficulties asking for support from their family caregivers, but on the other hand the same seniors also sometimes appear to be little flexible (with respect to what is done, when it is done, how it is done, if mistakes are made). Therefore, better communication between both actors and perhaps a little bit more flexibility on the part of the senior with respect to the care could result in a better relationship, which is built on reciprocity.

Last, we find that the impact of the restrictive measures taken to deal with the COVID-19 pandemic strongly depends on the specific situation. While some seniors and family caregivers experienced no negative impact, others did. In this respect, we first find that the physical contacts of all seniors significantly decreased, because the latter restricted their own social contacts or because some professionals no longer came, and day centres were closed. Moreover, the social contacts also changed and were less pleasant: they became less frequent, less long, and people needed to wear a mask and respect the physical distance. Therefore, many seniors indicated that they felt lonelier during this period. However, for certain seniors the decreased physical contact did not have a particularly negative effect, namely seniors who lived in couple, seniors in a high state of dementia who did not (fully) realise what was happening, and seniors who saw other types of contact (through ICT) increase in intensity. With respect to the family caregivers, we see that the burden of care significantly increased for family caregivers of seniors with high care needs, if they took over many tasks that before were done by professionals or family caregivers that live further away, and if they could no longer appeal to sitters or day centres through which they had less moments to rest.

4.1 Policy recommendations

Various principles of the empowerment framework (De Witte & Van Regenmortel, 2019a) appear to be very important in order to realise person-centred care for older seniors and their family caregivers: having a positive attitude, participation, inclusiveness, integral, structure and coordination and a pro-active, outreaching working method. Based on this research, we formulate a number of policy recommendations that aim to increase the quality of life of community-dwelling older seniors with care needs and/or their family caregivers. In this respect, we find that one-size-fits-all measures do not exist, and that we need a wide range of measures, which are all distinct pieces of the puzzle.

1. Increase the mobility of seniors by taking away structural barriers

From this research, we deduct that the mobility of seniors is strongly impacted by their physical and mental health limitations (problems walking, eyesight, hearing) which hinder them from going out and (indirectly) also from sustaining a social network. In this respect, it seems important to make sure those hindrances are taken away, for example by adjusting sidewalks to users of wheelchairs of walkers, and making sure those seniors can take public transportation or have access to affordable individualised transportation. With respect to the latter, we refer for example to Mobitwin, an organisation who aligns offer and demand between volunteer-drivers who want to accompany people with mobility limitations to their destination and back. In doing so, this organisation tries to alleviate social isolation among volunteer-drivers and their members by stimulating the mobility of their members and indirectly creating more social participation (De Witte & Van Regenmortel, 2019a).

2. Stimulate ‘moving in time’

Many of the respondents explain that they (will in the near future) have trouble to remain living in their own home due to their limitations. At the same time, almost none of them are willing to move to an adapted residence (an apartment, a service flat), and several of them explain that they would do almost anything to never go to a nursing home. Nevertheless, many seniors in Belgium do not live in a ‘caring neighbourhood’, and would presumably benefit from moving to such a neighbourhood with many services and shops in proximity, and where it might be easier to sustain a social network. Therefore, it seems appropriate to open this discussion and stimulate seniors in time to ‘move in time’.

3. Give professionals sufficient time to simply talk with seniors and detect needs

Most respondents find it important to have ‘a click’, a good connection with professionals (and volunteers), and they explain that ‘the talk’ with them is very important. Indeed, they sometimes see them as company. Therefore professionals should have sufficient time to talk to the seniors they visit because this is not only beneficial for the senior (because of the talk and company), but during those conversations professionals are able to detect various needs of both seniors and their family caregivers. This principle is for example adhered to by Atoll, a day centre where lonely and socially isolated seniors who live at home can spend the day. In their working method, the relationship between the professionals and seniors must be authentic by really listening to their remarks, talking and debating, having respect and having a relationship based on equality (De Witte & Van Regenmortel, 2019a).

4. ‘Triple One’

From our interviews we find that it is crucial for seniors to have at least one person with who they have a good contact, and on who they can count for practical issues at all times. This is in line with the insights from our third research report (De Witte & Van Regenmortel, 2020), in which we demonstrate that the impact of having at least one ‘good contact’ on feelings of loneliness is significantly more important than the exact number of contacts one has (one, two, three, ...). This is also the case regarding with how many other people seniors live together, the number of children one has, the number of activities one undertakes, the number of network members who live in a radius of 5 kilometres, and the number of network members with who they have at least one weekly contact.

As a result, we find that it is crucial that every senior has at least one person of reference, through which we propose the following goal, namely to give each senior at least one contact, once a week (‘Triple One’), which can be realised through a sort of buddy-system (~ Armen TeKort).

5. Enhance access to technological communication for seniors

Since the COVID-19 pandemic emerged, we have seen the many positive effects of technological devices to communicate with close ones. Therefore, it seems important to enhance the access to these devices among seniors by handing out those devices to seniors, and giving formations on how to use them.

6. Create a family care coordinator in all regions

This research report shows the many beneficial effects of the presence of a family care coordinator for family caregivers who care for seniors with high care needs. Indeed, those family caregivers can appeal to those coordinators to ask practical information about which services exist, but also to talk about social and ethical considerations. Indeed, the family caregivers find this role extremely valuable because those coordinators can offer a more neutral perspective on their situation which could help them make decisions (about which care to use), get all sibling in line, ... In this respect, Lopez-Hartmann *et al.* (2012, p. 14) state that it is important that a specific service at key moments monitors the family care situation, builds a relationship of trust and looks together for solutions:

> *‘Integrated support packages where the content of the package is tailored to the individual caregivers’ physical, psychological and social needs should be preferred when supporting informal caregivers of frail elderly. It requires an intense collaboration and coordination between all parties involved.’* (De Koker, 2018).

Hereby, it seems also interesting that the many professionals and volunteers who visit older seniors pass messages to the family care coordinator when they feel that either the senior or the family caregivers have certain needs. As a result, that family care coordinator can contact the family caregivers (and seniors) to talk about their needs and try to formulate a response. In this respect, it could be useful that all those actors belong to the same covering organisation which seems to enhance their communication.

7. Provide sufficient psychological support, and group discussions with other family caregivers

Several family caregivers of older seniors with high care needs explained that group discussions with other family caregivers in similar situations gave them both emotional and practical support. Indeed, it gives them the feeling that they are not alone in their situation and they can give each other practical tips to deal with specific difficulties. Moreover, through those discussions they can meet other people (social contact), and receive a more neutral perspective on their own specific situation and feelings of guilt: for example by receiving the feeling that they can still sometimes have fun with their family and friends, even while their partner has high care needs. These meetings could also help to deal with the emotional burden of seeing their close ones (physically or mentally) deteriorate. Hence, it seems appropriate to further stimulate those meetings and make sufficient publicity for them among family caregivers.

8. Invest in ameliorating the relationship between senior and family caregivers

From this research, we find that the relationship between seniors and family caregivers is not always perfect. Therefore, it seems important to try to ameliorate this relationship so that both parties understand each other's position better. In this respect, we find that many family caregivers find for example that they have the feeling that the seniors do not always fully appreciate their support, and certainly do not express it very often. This is problematic because they explain that this lack of demonstration of appreciation makes that the caring for the senior is not always a pleasant experience for them. In line with this, they also state that some seniors are little flexible and have high requirements concerning the care (when it is done, how it is done, ...), and do not always realise enough that the family caregivers have their own family and life. On the other hand, the seniors indicate that they often have difficulties asking their family caregivers for support. Therefore, it seems important to invest in ameliorating the communication, reciprocity and general understanding of each other's situation (for example through groups discussions or info sessions), so that both know what they can and cannot expect from each other.

9. Corona: invest in social relations, contact, group discussions, and keep day centres open

Due to the restrictive measures taken to deal with the corona pandemic, many seniors not only needed integrated information, advice and support, but also felt lonelier in that period. With respect to the latter, not only the physical contacts with family and friends decreased, but also many professional services no longer passed by and most day centres closed temporarily. This was difficult for several seniors because for some of them these are the only contacts they have, but also for family caregivers because those day centres allowed them to have a break that alleviates the burden of care. Therefore, for the family caregivers it would be good if some of those professional services would nevertheless remain open (while adhering to the corona-requirements) or would organise alternative activities (e.g. online). Further, it seems important to invest in communication, information and social contacts of seniors in general. This can be done by realising many of the above policy recommendations (such as investing in the use of technological devices, or 'moving in time'), but also by adding on the many grass root initiatives that saw light during the corona crisis, such as installing a central hotline for seniors (where they can ask all kinds of practical questions), letting various (social, cultural, sport, ...) organisations and also specific actors (e.g. neighbours, general practitioners, ...) work outreaching and contact the vulnerable seniors they know to discuss their needs, letting volunteers call older seniors simply 'to talk' but also to detect their needs, installing internet sites where people can find integrated and actualised information about which policy measures are taken, which services are available and where offer and demand can be aligned in a specific neighbourhood (for example for groceries and meals). Indeed, all these initiatives can help formulate an answer to the various (social, practical, emotional) needs of older community-dwelling seniors with care needs.

4.2 Further research

In this paragraph, we formulate a number of interesting options for further research. First, it would be interesting to focus more on ex-family caregivers: by gaining more understanding of the reasons why they stopped offering family care, we can detect more support needs of those actors. Second, more research is needed about family care of seniors in residential institutions:

> *'How do these family caregivers experience the residential in-take of the person in need? Which tasks do they (still) take on? Are there new tasks they take on? How is the collaboration with care professionals from those residential settings? Do the outcomes differ from family caregivers who provide support to persons who reside at home? Which support needs do these family caregivers have?'* (Bronselaer *et al.*, 2018, p. 43).

Third, further research could focus on the role of the motives to offer family care, and also on barriers for family care (e.g. financial, a lack of skills) and various contextual characteristics such as the availability of professional services or the specific social context (Bronselaer *et al.*, 2018). Four, more longitudinal research about family care in Belgium is needed. In this respect, SHARE could be an interesting source to gain more insight into the evolution of family care in Belgium by gaining insight in the prevalence, flux of family care (in and out), sociodemographic and socioeconomic characteristics of both older family caregivers and seniors with needs, ... Five, more geographical comparative research would be interesting whereby Flanders, Brussels and Wallonia are compared, but also international comparisons could be interesting. Six, given that more than 50% of the seniors in Brussel have a migration background, it would be interesting to gain more insight into family care among ethnic minorities and also family care in precarious situations. Last, it would be interesting to gain more understanding in care networks, the whole of the (formal and informal) care around a senior with care needs. In this respect, it would be interesting to research how the care comes about, which actors take on which tasks, if communication takes place and how, how all actors collaborate, how arrangements are made, ... in order to detect more support needs of both seniors and family caregivers.

REFERENCES

Anthierens, S., Willemse, E., Remmen, R., Schmitz, O., Macq, J., Declercq, A., …; DFarfan-Portet, M. (2014). Synthese. Ondersteuning van mantelzorgers - Een verkennend onderzoek.

Beke, W. (2019). *Beleidsnota. Beleidsdomein Welzijn, Volksgezondheid, Gezin en Armoedebestrijding 2019-2024*. Retrieved from Vlaams Parlement: https://www.vlaanderen.be/publicaties/beleidsnota-2019-2024-welzijn-volksgezondheid-gezin-en-armoedebestrijding

Belgian Health Care Knowledge Centre. (2019). KCE Report 313 Performance of the Belgian health system - report 2019. Retrieved from https://kce.fgov.be/sites/default/files/atoms/files/KCE_313C_Performance_Belgian_health_system_Report.pdf

Börsch-Supan, A., Brandt, M., Hunkler, C., Kneip, T., Korbmacher, J., Malter, F., …; Zuber, S. (2013). Data resource profile: the Survey of Health, Ageing and Retirement in Europe (SHARE). *International journal of epidemiology, 42*(4), 992-1001.

Boucher, L. (2016). What are the different types of population pyramids? Retrieved from https://populationeducation.org/what-are-different-types-population-pyramids/

Bourguignon, M., Degrave, F., Eggerickx, T., Ghilain, M., Leider, B., Lits, G.,… Sanderson, J.-P. (2016). *La gestion du vieillissement en Wallonie aux horizons 2025-2045: enjeux et prospective*. Retrieved from file:///C:/Users/u0083574/Downloads/rr17_-_la_gestion_du_vieillissement_en_wallonie.pdf

Bronselaer, J., Demeyer, B., Vandezande, V., & Boer, L. V. (2018). *Wat weten we (niet) over informele zorg in Vlaanderen? Voorstel voor het dichten van de cijfer- en kennislacunes*. Department Welzijn, Volksgezondheid & Gezin

Bronselaer, J., Festraets, D., Moons, D., Vandezande, V., Vanden Boer, L., & Demeyer, B. (2017). Het economisch welzijn en de economische waarde van Vlaamse mantelzorgers.

Cès, S., Flusin, D., Schmitz, O., Lambert, A.-S., Pauwen, N., & Macq, J. (2016). *Mantelzorgers van thuiswonende ouderen in België: een cruciale en complexe rol. Data onderzoek*. Retrieved from file:///C:/Users/u0083574/Downloads/3427_Data_Samenv.pdf

De Koker, B. (2018). Variaties op mantelzorg.

De Witte, J., & Van Regenmortel, T. (2019a). SILVER EMPOWERMENT. Loneliness and social isolation among elderly. An empowerment perspective.

De Witte, J., & Van Regenmortel, T. (2019b). SILVER EMPOWERMENT. Resilience of vulnerable elderly. A narrative research approach.

De Decker, P. (2020). Waar is het goed wonen voor ouderen? Retrieved from https://sociaal.net/opinie/waar-is-het-goed-wonen-voor-ouderen/

De Witte, J., & Van Regenmortel, T. (2020). *Silver empowerment. A quantitative picture of loneliness among elderly in Belgium and Europe*. Retrieved from https://hiva.kuleuven.be/nl/nieuws/docs/tvr-18-tse-lssrc1-o2010-loneliness-of-people-with.pdf

Deboosere, P. (2020). *Lang leve de vergrijzing*: EPO.

Department Welzijn, V. e. G. (2013). *De kracht van het engagement. De vermaatschappelijking van de zorg in de dagelijkse praktijk*. Luc Moens

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

Niedzwiedz, C. L., Richardson, E. A., Tunstall, H., Shortt, N. K., Mitchell, R. J., & Pearce, J. R. (2016). The relationship between wealth and loneliness among older people across Europe: Is social participation protective? *Preventive medicine, 91*, 24-31.

Royers, T. (2010). *Factsheet IV: Ontspoorde zorg, risico op ouderenmishandeling bij mantelzorg*. Retrieved from Vilans: https://www.aanpak-ouderenmishandeling.nl/doc/Factsheet-Ontspoorde-zorg.pdf

Scheepmans, K., Debaillie, R., De Vliegher, K., Paquay, L., & Geys, L. (2004). Succesfactoren_en_hinderpalen_in_de_thuiszorg: de beleving van de mantelzorgers.

Steyaert, J. (2020). Dementiezorg in tijden van corona: uitdagingen voor vandaag en morgen. Retrieved from https://www.dementie.be/themas/coronavirus-en-dementie/dementiezorg-en-corona-uitdagingen-voor-vandaag-en-morgen/

Steyaert, J., De Wachter, L., & Dely, H. (2020). Dementie in tijden van corona. Retrieved from https://www.dementie.be/wp-content/uploads/2020/07/20200715_DementiezorgInTijdenVanCoronaEDV20.pdf

Studiedienst Socialistische Mutualiteiten. (2016). *Enquête ouderenzorg*. Retrieved from

Thys, R., & Vermeulen, S. (2018). *Zorgkracht in persoonlijke netwerken van Brusselaars*. Retrieved from file:///C:/Users/u0083574/Downloads/Cahier-5_zorgkracht_v08_met_cover-druk.pdf

Van Audenhove, C., & Declercq, A. (2007). De mantelzorg. Over zorglast, veerkracht en het belang van een goed relatie.

van Regenmortel, T. (2011). *Lexicon van empowerment*. Retrieved from Marie Kamphuis Stichting:

van Boekel, L., Stoop, S., & G. Luijkx, K. (2020). Uitbraak COVID-19 in de verpleeghuiszorg. Wat kunnen we leren uit de literatuur van andere rampen of crisissituaties? *Tijdschrift voor gerontologie en geriatrie*. doi:10.36613/tgg.1875-6832/2020.03.01

Vanderleyden, L., & Moons, D. (2015). *Informele zorg in Vlaanderen in dalende lijn?!* : De Studiediens van de Vlaamse Regering

Vermeerbergen, L., & Van Hootegem, G. (2020). Woonzorgcentra na corona: kleine teams, kleine wooneenheden.

Vermeulen, B., & Declercq, A. (2011). *Mantelzorg vanzelfsprekend? Over zorgervaringen en noden van mantelzorgers van kwetsbare ouderen*. Retrieved from file:///C:/Users/u0083574/Downloads/SWVG.%20Feiten%20&%20Cijfers.%20Mantelzorg,%20vanzelfsprekend!_%20Over%20zorgervaringen%20en%20noden%20van%20mantelzorgers%20van%20kwetsbare%20ouderen.pdf

Vermeulen, B., Declercq, A., & Spruytte, N. (2011). SWVG Feiten en Cijfers 17_Met de mantel der liefde.

Vlaamse Ouderenraad. (2016). *Advies 2016/6 op het Ontwerp Vlaams Mantelzorgplan 2016-2020 'Nabije zorg in een warm Vlaanderen'*. Retrieved from file:///C:/Users/u0083574/Downloads/Advies%202016-6_%20Vlaams%20Mantelzorgplan%202016-2020%20(1).pdf

Vlaamse Ouderenraad. (2018a). *Advies 2018/1 Op de Conceptnota 'Residentiële ouderenzorg, een échte thuis voor kwetsbare personen'*. Retrieved from https://www.vlaamse-ouderenraad.be/sites/default/files/downloads/2018-03/Advies%202018-1%20op%20de%20conceptnota%20residenti%C3%ABle%20ouderenzorg.pdf

Vlaamse Ouderenraad. (2018b). Dagprijzen woonzorgcentra stegen met 3,11 procent. Retrieved from https://www.vlaamse-ouderenraad.be/onderzoek/wonen-en-woonomgeving/dagprijzen-woonzorgcentra-stegen-met-311-procent

Vlaamse Ouderenraad. (2019a). *Advies 2019/3 Over een domeinoverschrijdend actieplan rond kwaliteitsvol wonen in de thuisomgeving, in elke levensfase*. Retrieved from https://www.vlaamse-ouderenraad.be/sites/default/files/downloads/2019-11/Advies%202019-3%20domeinoverschrijdend%20actieplan%20kwaliteitsvol%20wonen_0.pdf

Vlaamse Ouderenraad. (2019b). *Advies 2019/4 over de aanpak van eenzaamheid bij ouderen*. Retrieved from Brussel: https://www.vlaamse-ouderenraad.be/sites/default/files/downloads/2020-01/Advies%202019-4%20over%20de%20aanpak%20van%20eenzaamheid%20bij%20ouderen_DEF.pdf

Vlaamse Ouderenraad. (2019c). Nationaal Geluksonderzoek: 'Geluk is maakbaar'. Retrieved from https://www.vlaamse-ouderenraad.be/onderzoek/welzijn-gezondheid-en-zorg/nationaal-geluksonderzoek-geluk-maakbaar

Vlaamse Ouderenraad. (2019d). Ouderenbeleid: drie prioriteiten voor het nieuwe Vlaamse regeerakkoord. Retrieved from https://www.vlaamse-ouderenraad.be/wat-denken-we/verkiezingsmemoranda/ouderenbeleid-drie-prioriteiten-voor-het-nieuwe-vlaamse

Vlaamse Ouderenraad. (2020a). 75-plussers extra kwetesbaar voor psychische problemen. Retrieved from https://www.vlaamse-ouderenraad.be/onderzoek/welzijn-gezondheid-en-zorg/75-plussers-extra-kwetsbaar-voor-psychische-problemen

Vlaamse Ouderenraad. (2020b). Bezoekregeling woonzorgcentra doet heel wat stof opwaaien.

World Health Organization Center for Health Development. (2004). *A glossary of terms for community health care and services for older persons*. Retrieved from Geneva: https://apps.who.int/iris/bitstream/handle/10665/68896/WHO_WKC_Tech.Ser._04.2.pdf?sequence=1&isAllowed=y

Yates, J. (2015). Addressing isolation: the importance of integration and the role of institutions. *Quality in Ageing and Older Adults, 16*(1), 58-61. doi:10.1108/QAOA-11-2014-0039

Zorgnet Icuro. (2020). Vlaanderen investeert 25 miljoen in actieplan mentaal welzijn Zorgen voor Morgen.