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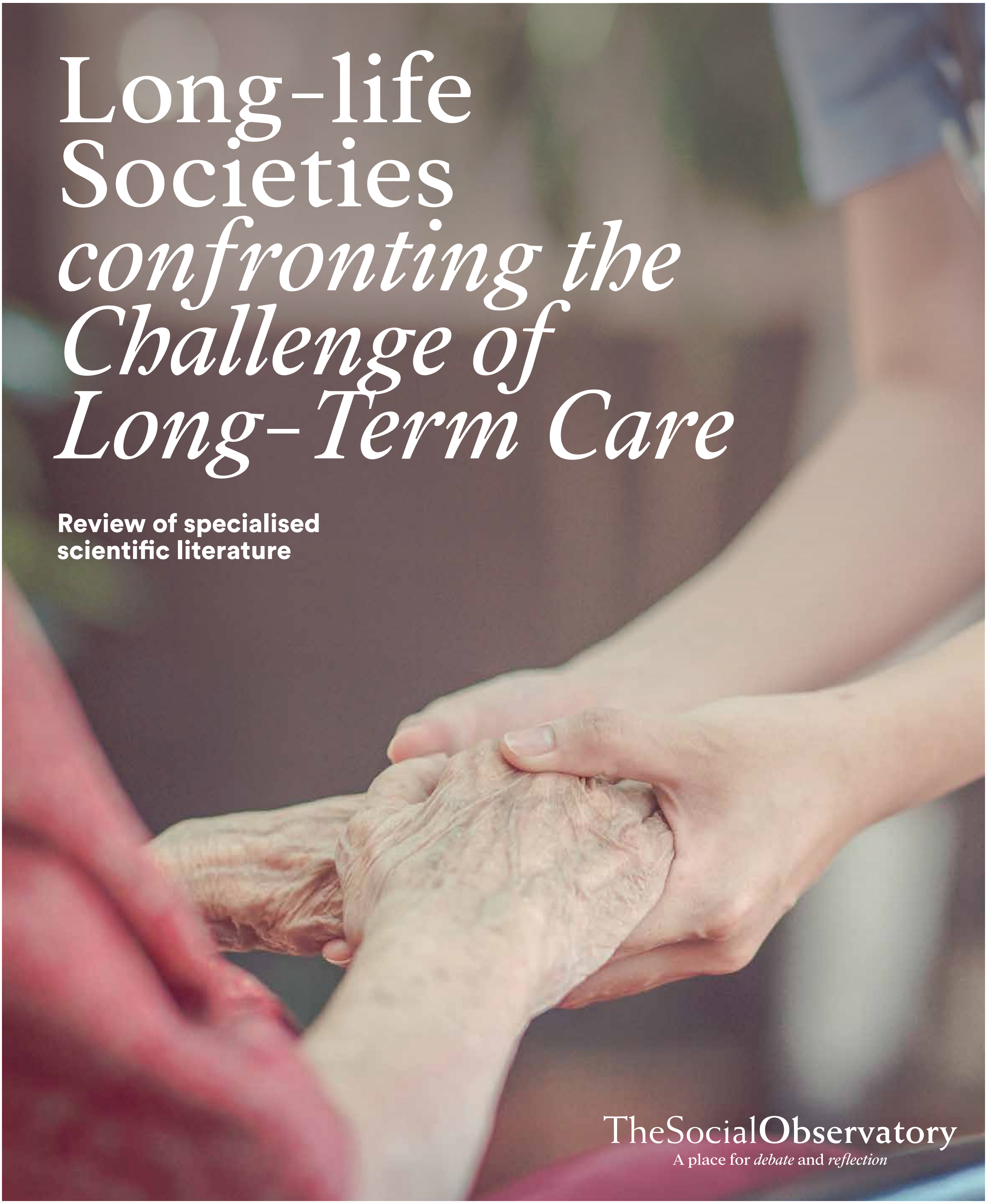

Long-life Societies *confronting the Challenge of Long-Term Care*

Review of specialised scientific literature

TheSocialObservatory
A place for *debate* and *reflection*

The Social Observatory of the “la Caixa” Foundation
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Table of contents

Executive *summary*

Having older, more longer-living people implies an increased need for a variety of person-centred resources

Key ideas

1. According to the World Health Organisation, long-term care (LTC) is a system of actions carried out by informal caregivers (family, friends or neighbours) or professionals (health, social or other), or both, in order to ensure that a person who is unable to perform basic daily life activities can independently maintain the best possible quality of life in accordance with their individual preferences and with the highest possible degree of autonomy, participation, self-fulfilment and human dignity. Respect for human rights must always be present.

2. Scientific advances in health and technology as well as improvements in the lifestyles of Europe's population have increased life expectancy to unprecedented levels and this poses a major challenge not only in health and social care, but also in areas such as caregiving, housing, the economy and, above all, public policy.

3. COVID-19 has greatly impacted the most vulnerable people and has placed the issue of care for the elderly and dependent persons at the heart of public debate. Particularly in relation to the respect that should be given to the rights and wishes of all elderly people, including those in their last moments of life and those living with some form of severe cognitive or physical impairment and/or high levels of dependency. Integrating public policies from various sectors around common objectives is extremely necessary but at the same time very complex. The need for coordination among the different systems has become clear during the COVID-19 pandemic, given that ineffective health and social care coordination leads to increased health care pressure, neglect and excess deaths.

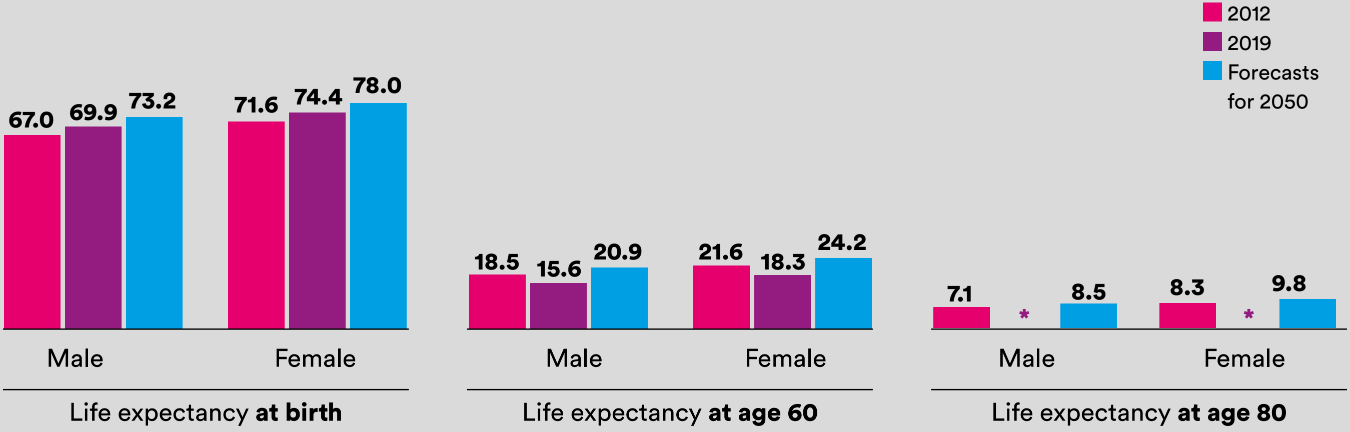
4. Health and social systems are a necessary part of the welfare state and are at the heart of the protection model. Adopting a socio-health care coordination model provides clear opportunities when it comes to caring for people: on the one hand, a comprehensive and integrative approach to people in which care services revolve around them and not the other way around and, on the other hand, the optimisation of public and private resources in order to assist people requiring long-term care.

⑤ Home care involves support services for people in a situation of dependency who wish to continue living at home. Ageing in one's place is a preference that has constantly been highlighted in scientific literature for all ageing people, including those in need of long-term care.

⑥ There are various resources and services for the prevention and care of situations of dependency and the promotion of personal autonomy in the catalogue of services of the Law on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency (Art. 15): telecare service, home help service, day/night centre service and residential care service. With the exception of residential care, the other services are focused on improving the quality of life of non-institutionalised people, thereby helping to extend the period of life at home.

Global ageing indicators :

Life expectancy



**No data are available for 2019.*

Source: World Population Prospects (2019). United Nations, Department of Economic and Social Affairs, Population Division.

IN THE WORLD

There are nearly **703 million** people over the age of 65 in the world and this number is expected to rise to over 997 million by 2050.

Life expectancy is increasing in the world and this can be seen in the table displaying data from 2012 and 2019 as well as forecasts for 2050. Clear differences by sex, with women having a higher life expectancy, can also be noted. These differences indicated almost 5 years of life expectancy at birth in the year 2019. In the case of people who are already 60 years old, their life expectancy in 2019 was 15-18 years longer and 20-24 years longer in 2020.

IN SPAIN

In the case of Spain, there were 9,183,000 people over the age of 65 in 2019 and this figure is expected to increase to 11,575,000 by 2030. **If the dependency ratio (ratio between dependent and active population) in 2019 was 32.2, this number is expected to be 43.2 by 2030.**

Proposals for action:

Rights and social role:

It must be ensured that **all people can age with dignity**, security, autonomy and privacy. Ample evidence exists of the many contributions that the elderly make to their societies, but ageist attitudes not only conceal these contributions, but also negate the human capital that the elderly represent as agents of change and of economic and social development.

Care must revolve around people and their needs:

The physical and social environments in which we live also influence healthy ageing. **Long-term care involves more than just meeting basic needs**, it is about preserving the rights of the elderly, their basic freedoms and human dignity. In order to do this, (formal and informal) caregivers require adequate training and support. Responsibility for long-term care must be shared among families, governments and other sectors.

Public policies:

The current debate around the issue of long-term care highlights the need for: (a) an **urgent review of the current care model for people requiring support** or care to enjoy a full life; (b) provide a variety of comprehensive ecosystemic responses; (c) increased public funding for various support and long-term care services, which is currently low and displays many differences in Spain's various Autonomous Communities; d) increasing the available resources to ensure adequate care in the different places where people wish to live, and e) a need to coordinate the various agents involved in care (families, social services, local services, home help, primary and specialised care, hospitals, volunteering and community participation).

Ageing at home: challenges and opportunities:

People prefer to age at home with quality of life conditions, but some require specific continuous care that needs to be provided in residential settings. The number and variety of home care resources must be increased and common standards must be applied for residential care requirements at a state level. Dependency care must be geared towards improving the quality of life of people. Care in situations of dependency is a source of economic development and job creation.

Care network:

Socio-health care coordination is required in order to optimise resources and provide comprehensive care for people. There needs to be a discussion on socio-health care and this implies physical, cognitive, emotional and social care.

A mosaic of needs:

The population group comprising people over 65 is **not a homogeneous group upon which to design and implement generic policies**. It represents as much diversity as any other social group, including particular and specific interests. Furthermore, a gendered approach to care and ageing is required, given that there are more women caregivers and more elderly women in a situation of social fragility and vulnerability.

Chapter 1

Introduction to *long-term care*

The speed of medical advances taking place has overtaken public policies when it comes to longevity

One of the defining characteristics of today's societies is that they are becoming increasingly long-lived. We have gained years of life and this often means the appearance of chronic diseases, disability, loss of autonomy and age-related dependency situations. Vulnerability is intrinsic to human life. Life expectancy is one thing, but healthy life expectancy is another. Biotechnological advances have made it possible to extend life expectancy to unprecedented levels (83.3 years in Spain). This fact, despite being an undeniable success, poses one of the greatest challenges for developed countries (and especially for public policies), which is to reflect this medical progress in the quality of life of the elderly.

Population ageing is an unprecedented challenge for countries throughout the world. It affects all areas, not only health or social care, because it has economic, employment and other consequences that will become increasingly more pronounced. It is estimated that there will be 16,000,000 people over 65 years of age in Spain by 2050, a figure representing 33% of the total population.

Today more than ever, this issue is at the heart of public debate following the impact that COVID-19 has had on the elderly throughout the world, especially among the most vulnerable. Higher rates of illness and mortality, which are four times greater than general rates, and especially the difficulties in managing this situation have brought the social implications of this health crisis to the forefront. Particularly in relation to the respect that should be given to the rights and wishes of the elderly, as well as in their last stages of life and when they have some kind of severe cognitive or physical impairment and high levels of dependency.

The longer the life expectancy of a society, the greater the need for providing long-term care

The generation currently reaching retirement age, known as the "baby-boomers" because of the demographic explosion they represented, is the largest generation there has ever been, with a significantly higher educational and socio-economic level than the generations that preceded them. This inevitably leads to adapting existing resources to their new needs and interests (Vitorino et al., 2013), given that, although increased life expectancy has been paralleled by the better health of people reaching old age, the number of years that a person can live in a situation of dependency because of morbidity and mortality has also increased (Pearlin & Zarit, 1993; Rogero, 2010).

People now reaching retirement age can aspire to live half of their remaining years in good health, but as age increases, the risk of dependency increases, as does the length of time an older adult may need long-term care (hereinafter referred to as LTC).

This reality poses a threat to the systems providing services in situations of dependency and places LTC at the forefront of public discussion. We refer to LTC that only affects the elderly throughout this study. According to the World Health Organisation (WHO), long-term care is a system of actions performed by informal caregivers (family, friends or neighbours) or professionals (health, social or other), or both, in order to ensure that a person who is unable to perform basic daily life activities can independently maintain the best possible quality of life in accordance with their individual preferences and with the highest possible degree of autonomy, participation, self-fulfilment and human dignity. Respect for human rights must always be present.

Several factors influence the use and even the intention of using LTC: socio-demographic variables (age, gender, educational and economic level, geographical environment), functional level and support needs, supply of resources and local services, availability of informal care, available self-care programmes and lifestyle.

The aim of this report is to provide a description based on a systematic review of the literature of the various models of providing LTC aimed at the elderly (in this case, people aged 65 years and over) that can help to provide us with a snapshot of the main existing resources in terms of the places in which they are implemented.

An international comparative analysis of the various LTC models is an impossible task, given that different countries have different service delivery regimes, different rates of public-private coverage, offer a catalogue of services that varies greatly from one country to another and even their nomenclature and regulations are extremely varied. Several patterns can be observed in some countries in terms of public spending (Northern European countries, Central European countries, Mediterranean European countries, Eastern European countries) and a shift from institutional care to home-based care, as well as a greater or lesser commitment to innovation. GDP investment and coverage varies greatly in different countries, from major investments in countries such as Denmark to smaller investments in Poland. We can also focus our attention on the exchange of support or intergenerational solidarity, observing a greater importance of the family as a provider of support in Southern European countries. Governance policies operate at different levels. In Spain, the regulations governing LTC and the budget allocated to it vary at the level of each Autonomous Community or municipality. This report will therefore provide several examples without claiming to be exhaustive. Health and social services in some LTC systems are linked and in others, as in the case of Spain, they are separated.

Coordination among systems

Population ageing and a rise in the number of people with age-related chronic diseases, in addition to changes in the family and work environment, have increased the need to organise and coordinate health services with social services. The idea is that there should be a holistic approach to the services focusing on people. Socio-health care arises from the demand for care for people throughout their life cycle, whether or not they are in situations of dependency, and not only to attend to acute or chronic diseases, but also, above all, to prevent, care for and cure. Certain problems that may sometimes be considered social at the beginning ultimately become health problems in the medium or long term, such as, for example, loneliness.

The need for adequate coordination between health and social services has been the subject of many national and regional studies in Spain. The first of these was the Commission for the Analysis and Evaluation of the National Health System (Abril Report), which was followed by an agreement to consolidate and modernise the National Health System. The Law on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency establishes the principle of collaboration between social and health services in providing services to individuals. The White Paper on Social and Health Coordination in Spain also discussed this need.

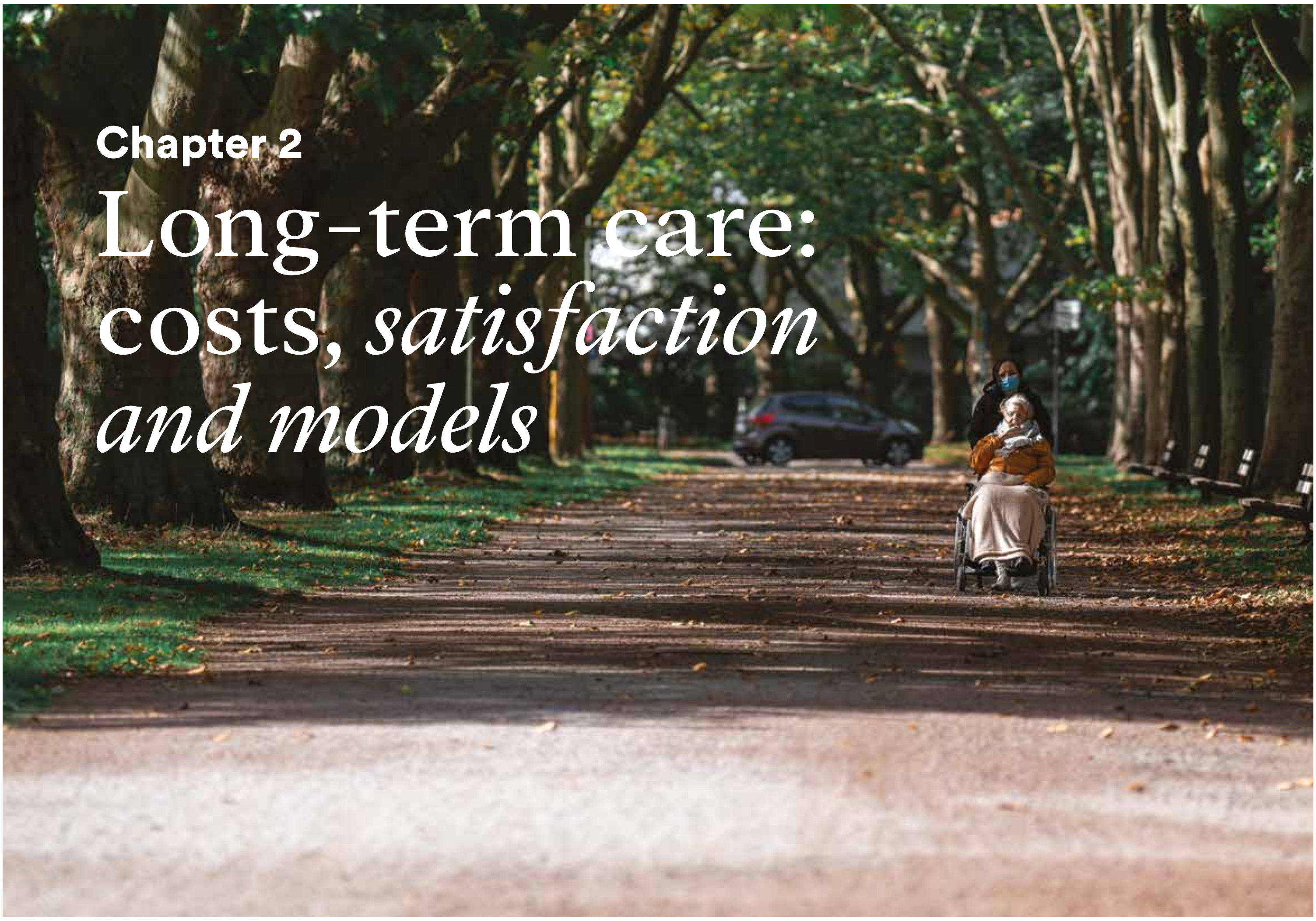
Nonetheless, little progress has been made despite all these studies, commissions, considerations and the need expressed by professionals in so many different forums. Several initiatives are worth mentioning here, such as the 2012 Strategy for Addressing Chronicity in the National Health System, the 2013 Document on Coordination and Socio-health Care of the Health Advisory Council, the 2015 Basic Document for Integrated Socio-health Care and the 2016 Strategy for Neurodegenerative Diseases. Some of these strategies have remained in their initial draft version and others have not been approved or there has been no budget to implement them. Several other strategies have been developed by Autonomous Communities with relative success.

Integrating public policies from various sectors around common objectives is as necessary as it is complex. The need for coordination between different systems became evident during the COVID-19 pandemic, given that ineffective socio-health coordination leads to increased pressure on health care.

According to the report published by the CSIC (Del Pino et al., 2020), "intersectoral (non-)coordination in many parts of the national territory has proved to be one of the key explanations of the magnitude reached by this crisis, both in the political-administrative sphere (Ministries and Regional Ministries) and in the organisational sphere (residences and health centres)".

Health and social systems are an essential part of the welfare state, located at the heart of the protection model. Adopting a socio-healthcare coordination model represents clear opportunities in the care of people that can be summarised in two points: a comprehensive, integrated approach to people in which care services revolve around them (and not the other way around) and the optimisation of public and private resources allocated to the care of people requiring LTC.

Integrating public policies from various sectors around common objectives is as necessary as it is complex. Ineffective socio-health coordination leads to increased pressure on health care



Chapter 2

Long-term care: costs, *satisfaction and models*

Long-term care, a growing need for increasingly more people over longer periods of time

There is one existing reality beyond the diversity of meanings that lies behind each concept of the LTC universe: increasingly more people are going to require long-term care and for longer periods of time. In a context of increasingly longer-life societies and low birth rates, maintaining and extending LTC is both a growing need and a growing challenge (Brainard et al., 2020). Innovation is urgently needed in order to create new and diverse services and resources.

Although care coverage has generally increased and there has been greater interest and endeavours in recent years to move towards the model of Person-Centred Integrated Care (PC-IC), there is also a growing concern that the cost of maintaining the quality of life of the elderly cannot be sustained (Rodriguez, 2004; Codorniu, 2007; Sáez et al., 2008).

The Person-Centred Integrated Care model focuses on the individual and advocates comprehensiveness as opposed to fragmented services. It is necessary to know the needs and preferences of people in order to be able to offer them the most suitable services and, furthermore, these may change over time.

Costs of long-term care in Spain: a challenge requiring greater attention from society

Analysing LTC models cannot ignore their costs and the ways in which they can be funded. The increased longevity of the population entails an increase in public spending associated with chronic illnesses, situations of dependency and care. An example of this is the implementation and development of Law 39/2006, of 14 December 2006, on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency, which was created with the aim of extending and improving the social protection system for the care of dependent persons. It was initially estimated that it would entail a significant increase in social spending of between half a point and one point of GDP, positioning it at around 1% (Codorniu, 2007).

However, according to data from the OECD (Health Statistics), the cost of services and benefits received by dependent persons in Spain in 2017 was approximately 0.7% of GDP, less than half the average for OECD countries (1.7%). On the other hand, the Ministry of Economy and Business forecasts that LTC spending will increase by 1.3 percentage points over the next 50 years to reach a level of more than 2% of national GDP. This is still a low level of expenditure, especially considering that LTC in Spain is primarily provided by families through informal care and that the value of this care is not included when calculating public expenditure on care for the elderly.

Despite the change of perspective in approaching the issue that occurred with the creation of the Law on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency, which at the time was a milestone in terms of coverage of needs, it should be noted that budgetary restrictions arising from the economic crisis of 2010 have had an impact in terms of delaying the stages in which its deployment had been planned. The drastic cuts in public spending (especially since Royal Decree 20/2012, of 13 July 2012, on Measures to Ensure Budgetary Stability and on Encouraging Competitiveness) have had repercussions of a restrictive nature that condition and will continue to condition the implementation of the Law (Ortega, 2013). The 2020 socio-health crisis caused by COVID-19 has brought to the table all these much-reported shortcomings and the fragility of the care model.

The cost of services and benefits received by dependent persons in Spain in 2017 was approximately 0.7% of GDP, less than half the average for OECD countries (1.7%)

Caregiver: female and singular

Despite the diversity in the intensity of social spending, the range of existing resources is quite similar among countries, and it is also noticeable that both dependent persons and caregivers (understood in the broadest sense, equivalent to the Anglo-Saxon concept of “care”) are mostly women at an international level. Two thirds of the people receiving LTC are women, because they have a longer life expectancy and often more years in a situation of dependency, given that they are not free of disability throughout their entire life.[1]

Whatever the model analysed, whether at home (formal or informal care) or in a centre, it is mostly women who perform these tasks (Kramer & Kipnis, 1995). Moreover, they are often the sole caregivers. Data from the Autonomy and Dependency Care System (SAAD by its Spanish acronym), which analyses monthly figures on applications, beneficiaries and benefits, report that 89% of non-professional caregivers are women (53,000 people according to data from October 2020).

According to the Labour Force Survey (EPA by its Spanish acronym) of the National Institute of Statistics (INE by its Spanish acronym), only 5% of caregivers are men. It should be borne in mind, however, that the EPA only shows the tip of the welfare iceberg, which is that of professional care, leaving the bulk of unpaid care for dependent persons hidden below the surface (Rogero, 2010). According to the Ministry of Health and Equality, three quarters of primary caregivers are women and there is similarly a notable bias in terms of origin and social class (Razavi, 2007).

We will not go too deeply into a definition of care here as this would be too extensive, but we will say that care implies a relationship with the other in which the wishes and needs of the recipient must be taken into account as a guide for action. The person is the subject of care and this is important to emphasise, given that it implies respecting the other as an interlocutor, a person with dignity and rights, always providing good treatment based on an ethic of care. Care begins with recognising the needs of the other (caring about), assuming responsibility for care (caring for) and providing care (caregiving). And there are various dimensions to this care: personal, social and political.

Caring means providing help and support to those who need it, taking into account what is important for people, their life history, applying the necessary professional and/or technical knowledge, accompanying, guiding, facilitating, making decisions and also using technology to improve the quality of life.

But can machines replace human care? The use of information and communications technology (ICT), the Internet of Things (IoT), wearables and robotics in care is increasing daily in today’s technological world. Assistive robots, caregivers and even robots to alleviate loneliness. Robots to keep in touch with the family, to monitor health, to connect with emergency services if alarms are triggered. Mechanical robots, robotic surgery assistants, robots that look like animals or humans… a veritable booming industry revolving around care.

But for technology to be universal, acceptable and accessible to all, it must be designed with the people who are going to use it in mind (Poveda et al., 2019), training them according to their rhythms and designing the new tools according to their digital skills.

[1] According to SAAD data of October 2020, 65% of the beneficiaries of a dependency benefit are women and 73% of those are over 65 years of age.

There is a growing interest in user satisfaction regardless of the residential environment in which care is received

In terms of residential care, therefore, two main LTC service provision models can be distinguished and these will be expanded upon in the following chapters. First, there is home-based care, which may be provided by a family member of the person requiring care (referred to as an “informal caregiver” or “non-formal caregiver”) or by a specialised worker (“formal caregiver” or “professional caregiver”, with the provision of public or private services). Secondly, there is care provided in institutionalised settings, such as residential homes, medium- or long-stay care homes and sheltered housing or flats.

Reviewing the literature cannot generally determine that any one of these models is per se better than the others, as it depends on the specific needs and conditions of each individual situation and person. Furthermore, these can change and vary over time. The important thing is the complementarity of resources and services. It is therefore worth noting that the focus of social and political debate in recent years has increasingly centred on the degree of satisfaction of the person using the services, with an increase in research or studies focusing on aspects that influence people’s emotional states, such as the quantity (and especially the quality) of people’s meaningful social relationships or the absence of these, leading to unwanted loneliness or social isolation. Indeed, a greater availability of support networks (people to rely on and relate to) and social networks in general is associated with a lower likelihood of admission to residential care (Giles et al., 2007) and with a better state of health (Luanaigh & Lawlor, 2008).

Various long-term care models in Europe have distinct regulatory regimes

In terms of sector regulation, supervision of residential care in Europe is poor and three different regulatory regimes can be identified: the Nordic countries have a self-regulatory approach; Central Europe, the UK and Ireland follow straightforward regulation that sets out what is permitted and what is illegal, and, finally, the Mediterranean and Eastern European countries. By widening the field of analysis, it can be seen how it is possible that the regulation of each region derives simply from the organisation of LTC services in each particular country. Therefore, the use of self-regulation in Scandinavian countries is more broadly associated with the philosophy of the welfare state, while the very nature of regulation in the UK and Ireland focuses on quality assurance rather than quality improvement, a methodology more commonly used in countries with highly privatised services (O’Dwyer, 2015).

Looking further into the Mediterranean model, Italy and Spain are characterised by a relatively high level of demand for LTC, a relatively feeble public endeavour in terms of formal care services and a considerable level of informal care provision (mostly through families), with a reorganisation of the LTC system through a “decentralisation” of social care functions from a national to a regional/local level (less fragmented in Italy than in Spain).

Funding in Spain is mainly based on tax revenues, but also in some cases on fees and co-payments. The Law on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency determines that people who are declared "dependent" and are granted a degree of dependency (1, 2 or 3[2]) may receive (Art. 14) services either directly (provided through the public range of provisions of the Social Services Network of the Autonomous Communities through public or private centres and services) or a financial benefit of a periodic nature if care through a service is not possible. This benefit is linked to the acquisition of a service accredited by the Administration (appropriate to the beneficiary's needs), as the Law only exceptionally provides for receiving a financial benefit for care by non-professional caregivers (primarily relatives of the dependent person), although this exceptional nature will be assessed in the following chapter.

Although regional governments regulate these measures and local authorities, as well as mostly non-profit private suppliers, provide them, it must also be noted that most LTC is performed by families (especially women) and therefore remains outside the scope of regulation and is of an exceptional nature, unregulated and highly dependent on migrant workers (mostly privately hired by the families of dependent elderly people), accounting for approximately 80% of all privately hired domestic helpers in Italy and 60% in Spain (Casanova et al., 2017; Barocca & Pinazo-Hernandis, 2013). It is therefore important to note the number of workers in the LTC sector with low levels of education: 15% in Germany and 18% in Austria or the UK, but 33% in Denmark, 39% in Spain and 46% in Italy (León et al., 2016).

> *Most LTC is performed by families (especially women) and therefore remains outside the scope of regulation and is of an exceptional nature, unregulated and highly dependent on migrant workers (mostly privately hired by the families of dependent elderly people)*

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[2] According to the Law (Art. 2.2), a *person in a situation of dependency* is an individual in a permanent situation that prevents them from performing basic daily life activities and therefore requires significant help from another person or persons to perform these, establishing 3 degrees of dependency (Art. 26): degree 1: moderate dependency, people requiring help to perform several basic daily life activities at least once a day; degree 2: severe dependency, people requiring help to perform several basic daily life activities two or three times a day, but not requiring the permanent support of a caregiver; degree 3: high dependency, people requiring help to perform several basic daily life activities several times a day and requiring the indispensable and continuous support of another person due to their total loss of autonomy. This is known as a "highly dependent person".

Chapter 3

Home *care*

Strong preference for remaining at home as long as possible during the ageing process

Home care generally refers to a wide range of support services for people in a situation of dependency wishing to continue to live at home (ageing in place) and is the preference highlighted in the scientific literature for people requiring LTC. The care under this banner ranges from support services for basic activities of daily living (BADL), personal care and other household tasks to highly skilled professional care.

In financial terms, staying at home implies savings for the state compared to staying in a residential care home with public places (Chappell et al., 2004). This can be explained by various factors, including wage costs and the degree of coverage (Zalakain, 2017).

When it comes to the Spanish model, benefits can be aimed at financially compensating informal caregivers or providing an LTC service performed by a professional. Support services for situations of dependency at home are based on care for people requiring continuous assistance to perform various BADL, such as dressing, washing, cleaning the home, helping to do the shopping for food or medicines, or accompaniment on other outings from the home. The steady rise in the number of LTC activities (whether formal or informal) therefore necessarily entails increased coordination of social and health services (Low et al., 2011).

Putting health care aside for now, home care can be provided by a public or private home help service (SAD by its Spanish acronym) professional or by an informal caregiver (or several) hired by the family, or directly by one (or several) family members acting as non-professional caregivers.

Degree of dependency and relationship with the family are determining factors when it comes to defining type of long-term care provided

Another important area of analysis that appears in the literature consulted is the existence of situations of recognised dependency, which may be moderate (grade 1), severe (grade 2) or major dependency (grade 3). As described in the Law on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency, the amount of formal and informal LTC services required increases as dependency increases. It is therefore worth noting the importance of the financial status or close family environment. Informal care increases in the case of a family caregiver who can handle care, while formal care increases and the presence of a single-family caregiver is less common if there is sufficient financial means.

Socio-cultural (and economic) determinants also strongly influenced the choice of one or other care model, with clear differences in the preferences of the European population. Thus, a more frequent use of informal care alone is found among older adults with functional limitations in Mediterranean countries, the Czech Republic and Germany (Eichler & Pfau-Effinger, 2009), which can be understood because of the great importance of family in these societies, which leads to a high perception of family responsibilities. The compensation mechanism that occurs when parents reach old age and children return the care received years before (Pinazo-Hernandis, 2005) is in fact also reflected in legislation and entails certain limitations for accessing formal LTC services (Lillo-Crespo & Riquelme, 2018; Suanet et al., 2012).

Main resource: non-professional caregivers

In general, when analysing policies for care in situations of dependency and LTC on the basis of the “care diamond” defined by Razavi (2007), which analyses the role of the family, state, market and third sector in providing these services, it is commonly noted that the greatest burden of care falls on the family, but it should be emphasised that non-professional caregivers play an important role in choosing the type of services assigned to the dependent person (Hunter & MacPherson, 1993).

Informal care in Spain plays an important role in the Law on People in a Situation of Dependency, given that 80% of people in situations of dependency receive informal care alongside the dependency benefit. Age, marital status (married), place of residence, specific health variables (presence of circulatory, respiratory or musculoskeletal diseases) increase the probability of receiving informal care (Del Pozo & Sotos, 2012).

Following along these lines, and on the basis of observing the job market, a significant fact that allows us to approach the type of LTC provided in the various countries is the importance of domestic service workers, given that most of them are dedicated to care for the elderly and people in situations of dependency (although not exclusively, as they also work in the childhood and family or disability areas).

Thus, if we compare the percentage of the population employed in residential social services, non-residential social services and domestic services, we can see that in Northern European countries, alongside the Netherlands and France, 8-12% of the total employed population works in the social services sector, while the European average is around 5% (and 3% in Spain). Nonetheless, the most remarkable aspect is the importance of domestic service workers, who are practically residual in the Nordic countries and account for only 1% of the European average, while in Spain and Italy they exceed the volume of workers in the social services sector. More than 50% of the workforce in the LTC sector is made up of domestic service workers (Zalakain, 2017) in Mediterranean countries.

Based on the significance of each of the agents (family, state, companies, third sector) in providing LTC, three types of intervention systems can be identified: shared, semi-shared and unshared (Rogero, 2010). Most European countries enjoy a shared system thanks to the development of welfare states throughout the latter half of the 20th century, although current political divergences impede any standardisation of LTC models in the EU, with notable differences, as we have seen.

Focusing on Spain, although the Law on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency only provides for receiving a financial benefit for care by non-professional caregivers as an exceptional measure, the reality is that most benefits in the field of LTC are in the form of aid for families as informal caregivers or for payment of other external caregivers, rather than allocating specific services. According to data from the Autonomy and Dependency Care System (SAAD by its Spanish acronym) of 31 October 2020, a total of 1,116,561 persons were beneficiaries of a dependency benefit. The majority of beneficiaries are over 80 years of age (53.7%), followed by those aged between 65 and 79 (18.1%). This means that almost 75% of people in a situation of dependency are aged 65 or over. This system of care for dependent adults has a budget of 9.5 billion euros, 58% of which are financial benefits.

In general, each person benefitting from the Law on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency receives an average of 1.27 benefits, with a total recorded number of 1,416,730 benefits broken down as follows: 31.5% receive a financial benefit for family care (PECEF by its Spanish acronym), 17.74% a telecare service, 17.65% a home help service, 11.02% residential care, 10.84% a service-related financial benefit, 6.36% attend day/night centres, 4.33% receive services to prevent dependency and promote personal autonomy, and a residual 0.56% a financial benefit for personal assistance.

The SAAD data therefore contradicts the spirit of the Law on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency, which was to promote personal autonomy, demonstrating how the main mechanism of care for dependent adults in Spain is precisely the financial benefit to informal caregivers. Nonetheless, it is worth analysing to what extent the current measures provide real support to these caregivers and to what extent they make them direct beneficiaries.

But in an increasingly ageing society that has lower birth rates, a reduction in family nuclei (tending towards single-person households), increasingly distant families due to a greater number of family flows and a society in which the incorporation of women into the workforce is greater, the provision of informal home services by family members will necessarily become increasingly residual (Codorniu, 2007) and may lead to an increase in the use of formal services (Miralles & Rey, 2015). This is particularly important to bear in mind in view of the demographic challenge posed by increasingly long-life societies. It should be remembered that the composition and size of the social network of the elderly is age-related: as age increases, the number of potential caregivers in the social network decreases (Rogero, 2009).

This trend towards more formal care to the detriment of non-professional caregiving can already be noted in Central and Northern European countries. Some studies attribute the causes to the weakening of informal solidarity ties (possibly due to the demographic processes discussed above) and the greater ease of access to formal care at home in these countries (Swinkels et al., 2016).

In an increasingly ageing society that has lower birth rates, a reduction in family nuclei, increasingly distant families due to a greater number of family flows and a society in which the incorporation of women into the workforce is greater, the provision of informal home services by family members will necessarily become increasingly residual and may lead to an increase in the use of formal services

The provision of formal LTC at home may be public (SAD by its Spanish acronym) or private, with the likelihood of receiving LTC from the public sector increasing if, as seen above, the dependent person is married, given that the partner acts as a link with social services (Del Pozo & Sotos, 2012; Rogero, 2009). The provision of care by social service professionals focuses on giving support to perform basic daily life activities and shopping. LTC services at home are complemented by health care, which can be provided by primary care teams or hospitals depending on the service required (from physiotherapy to monitoring with machines such as haemodialysis, for example).

A factor that most influences people's satisfaction within this field depends on the model of primary care provided, which may be integrated (in which doctors and nurses make home visits and are supported by programmes aimed at people and their family groups) or hospital-at-home units (in which several health team professionals are responsible for care in people's homes, both on demand and on a scheduled basis).

This second model displays a higher perception of service quality, largely because it involves a greater number of hours spent by the health professional per patient and is associated with a lower percentage of hospital admissions (Gorina et al., 2014). In fact, a systematic review of home-based primary care programmes in the USA shows that creating a link between the elderly and primary care providers leads to a significant reduction in hospital visits, improved detection of age-related syndromes, improved patient and caregiver quality of life and increased participation in end-of-life care decision-making (Stall et al., 2014).

Following along these lines, an under-developed aspect in the scientific literature is that of analysing the sectorised model of delivery of social and health services, in which the district, neighbourhood or health area is divided into geographical zones in order to make the travel times of professionals attending the people in that particular health area more efficient. For example, building on the management strategies of the private system, one non-profit organisation implemented a system of "neighbourhood care" (*Buurtzorg* in Dutch) that helped establish relatively autonomous teams of 10-12 professionals providing medical care and home support to a stable set of people living in the same neighbourhood. This change allowed for a more frequent relationship between the professional and the person receiving services (Cohu et al., 2006), more care time that can be devoted by professionals (Van der Boom, 2008) and, consequently, greater professional engagement (Johansen & Van den Bosch, 2017). The benefits displayed by this model and the cost reduction it entails (Gray et al., 2015) make it attractive as a replicable initiative.

In Spain, it is worth noting the *superilles socials* (social superblocks) project, a strategy for transforming public space with the aim of allocating part of the space used for vehicle transport to the use of citizens, based on a new model of fairer and healthier public space, with a proposed network of green hubs extending throughout the city, a network where walking routes are prioritised, linking green areas and facilities in a safe and friendly manner for people. So-called "care superblocks" comprise small professional teams of between ten and fifteen professionals caring for 40-70 people living in the same residential area, covering between 3 and 6 blocks. This system makes it possible to create stable care communities that improve the quality of care and the working conditions of professionals. There are currently eight care superblocks in Barcelona caring for 550 people and implementation is expected to be extended throughout the city to more than sixty teams in the coming years.

A series of services encouraging permanence at home

As noted above, the catalogue of services of the Law on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency (Art. 15) includes Services for the Prevention of Situations of Dependency and the Promotion of Personal Autonomy. These comprise a Telecare Service, Home Help Service or SAD (for home and personal care needs, which we discussed in the section on formal care), Day/Night Centre Service and Residential Care Service, although the data presented shows that these are underdeveloped.

With the exception of Residential Care, the remaining services are focused on improving the quality of life of people who do not reside in institutions, thereby helping to extend the period of life at home.

Telecare as a source of security for people in situations of dependency and their relatives

Home telecare is a service that does not directly provide health or social care, but rather a rapid, efficient and personalised management of the resources available in a home setting through an electronic device (which can be a medallion that the person wears and a terminal or mobile phone). The person is continuously connected at home or outside the home to an alarm centre operator who has a database with all the necessary medical and personal information and who sets in motion a series of resources to help the person (López, 2004) if he or she presses a button to ask for help or if the system detects any kind of anomaly (for example, if he or she should have called at a certain time and has not done so).

Telecare ensures day-to-day life not only for the elderly, people in a situation of dependency, people convalescing from an illness or with chronic illnesses, but also for all those living alone and wanting the security of having the care they need in the event of an emergency. Telecare provides peace of mind in the event of any domestic accidents, as well as companionship and support. The service consists of a fixed device and a mobile button that can be operated from anywhere in the home. By simply pressing the button, the person contacts the Care Centre, which is available 24 hours a day, 365 days a year. It operates in a simple manner: in the event of any emergency or need, the person presses the device and one of the professionals from the Care Centre will attend to him or her, calling the contact persons and/or the emergency services if required.

The Telecare Service can be public (in Spain, 247,917 dependent persons enjoyed the service as of June 2020) or private, and helps mobilise relatives, neighbours, ambulances, fire brigades, local police, etc., a fact that provides security for both the people who have the service assigned to them and their relatives, helping to extend the period of time that an elderly person can live at home (Procter et al., 2016). Nonetheless, it should be noted that despite the immediacy in the provision of the service offered by contacting the Telecare professionals located in the Call Centres, specific problems have also been detected arising from the difficulties that these professionals may experience in mobilising precisely this network of relatives and neighbours (Roberts et al., 2012).

Telecare can depend on many gadgets to monitor dependent people, such as pillows or cushions that warn if they do not detect any weight on them after a certain period of time, or various sensors, such as a fridge opening sensor or smoke or fire sensors, which are extremely important for people with Alzheimer's disease, for example. But their use as part of the public telecare system is limited by a question of cost.

Telecare became an essential service for the care and companionship of people during the lockdown and the months of the pandemic that followed. Since the state of alarm due to the COVID-19 pandemic was announced, calls to Telecare services have increased for various reasons: fear, doubts about what to do or not to do, as well as to have someone to talk to, given that social isolation has been difficult to cope with for everyone, especially for the elderly.

Day or day-care centres as facilitators for maintaining physical and cognitive abilities

Day Centres, Day-Care Centres or Day-Care Facilities (with different names depending on their location) are places that offer during daytime hours comprehensive and individualised care to elderly people who usually have a moderate degree of dependency. The literature in this field is not very extensive and is based mainly on studies carried out on individual facilities instead of analysing the whole. The evidence seems to agree that attending Day Centres leads to an improvement or maintenance of physical and/or cognitive abilities (Araya et al., 2018).

In fact, although there is no consensus on this, there is evidence that greater attendance (more than once a week) at Day Centres is associated with improved quality of life (Bilotta et al., 2010; Iecovich & Biderman, 2013). That said, the availability of a tight family network is a key determinant for the elderly to decide whether to attend a Day Centre (Kim, 2014). In other words, people attending Day Centres have more frequent and daily social support (mainly family) than those living in residential homes or those living at home who do not attend Day Centres, and this greater social support leads to a significant reduction in levels of depression for all groups (Seddigh et al., 2020).

Night Centres, despite being included in the Law on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency, have hardly been developed at all in Spain. Another type of centre can be found in several Autonomous Communities and this is known as a “respite centre”, designed as a support programme for family members acting as non-professional caregivers. The purpose of this service is to improve the quality of life of family caregivers by providing them with time to rest (for example, during short holiday periods) or in the event of unforeseen family situations. Many residential centres offer Day and Night Centre places.

Given the therapeutic benefits of daily attendance at these centres, it is clear that COVID-19, lockdowns and closure of centres, the physical distance imposed after reopening, the use of masks and the resulting difficulties in communication and recognition of emotions, among other factors, have led to losses in functionality, cognition and increased depressive states of mind. There is much still to be investigated about the short-, medium- and long-term effects of the pandemic.

Potential of telemedicine and barriers still remaining for its full implementation

Complementing this idea of remotely monitoring people who opt for the “ageing at home” model mentioned in the section on Telecare, another service that has evolved considerably over the last few decades is Telemedicine (e-health), thanks to the development of new computer and imaging systems. It enables the use of communication technologies for remote diagnosis, monitoring and treatment of patients (Currell et al., 2008) and, according to some authors, it is crucial for providing effective decentralised healthcare with increased patient involvement and social demands (Koch & Hägglund, 2009).

However, while the computerisation and technologization of contemporary societies may have facilitated the integration of social and health care services, as well as reduced the number of trips by health professionals to follow-up specific acute or chronic pathologies, many of the elderly have been marginalised for not being digital users and a notable age gap in this area has been detected (Vancea & Solé-Casals, 2016).

The COVID-19 pandemic has again changed people’s relationship with technology, both in telework and digital health, telemedicine and telemonitoring.

The advantages of Telemedicine in the care of patients with COVID-19 are clearly manifold, limiting potential exposures and contagions both in emergency rooms and hospitals or primary care centres, as well as reducing the use of personal protective equipment. A systematic review published in 2018 (Shigekawa et al., 2018) evaluated the safety and efficacy of Telemedicine in the following clinical areas: mental telehealth, telerehabilitation, teledermatology, teleconsultations and others, such as oral anticoagulation management, nutrition and diabetic foot ulcer treatment, among others. According to this study, Telemedicine was found to be equivalent to a conventional doctor’s visit both in terms of diagnosis and therapy. Teleconsultations reduce hospitalisation and lead to more frequent yet shorter contact between doctor and patient.

Chapter 4

Care in *residential institutions*

Residential facilities

The literature on residential care is extensive and of high quality. A systematic review of research in this field helps to show that the focus of interest has historically been on assessing physical activity programmes, psychological interventions or medical follow-up in LTC residential facilities (Van Malderen et al., 2013).

There is a growing interest in determining and quantifying the variables affecting the state of mind and life satisfaction of residents. In this sense, institutions that consider people's wishes and develop lines of action aimed at empowering residents by reinforcing them to perform daily life activities, encouraging their participation and decision-making capacity and stimulating the maintenance or creation of a supportive social network – i.e. in line with Integrated Person-Centred Care – achieve a notable improvement in the quality of life of residents (Burack et al., 2012; Chen et al., 2019; Sullivan & Asselin, 2013; Wang et al., 2018).

There are also many limitations when it comes to obtaining a clear knowledge of the residential sector: there is no national body representing them, regulations are regional and there are major differences among them (ratio of professionals, type of professionals, etc.). Another major limitation is the difficulty in quantifying the number of elderly people in institutions in Spain, given that there is no figure on the subject, apart from approximations and estimates. The number of people living in elderly care homes can be observed from the official population and housing censuses of the National Institute of Statistics (INE by its Spanish acronym), although it is possible to calculate people living in other institutionalised LTC models (such as supervised flats, socio-health centres, etc.). These censuses also fail to distinguish whether these residences are publicly or privately owned or what percentage of recognised dependent adults are actually in institutions.

The INE data corroborates the evidence found in the literature, according to which there was an upward trend in institutionalisation in the early years of the 20th century that has nonetheless not been maintained. Based on data from the 2001 and 2011 censuses, it can be seen that, although the increase in the population over 65 years of age was 19.4%, the increase in the number of elderly people living in residential care homes[3] was a notable 180.6% (rising from 96,338 to 270,286). But this remarkable rise in percentage terms refers to only 3.3% of the elderly. According to an estimate by *Envejecimiento en red* (the CSIC's publication portal on ageing) based on its database of residences in 2020, 3.5% of the total number of elderly people were in institutions (322,180 people over the age of 65). This figure, however, is equivalent to 40.6% of the elderly with recognised dependency and receiving a benefit under the Law on the Promotion of Personal Autonomy and Care for People in a Situation of Dependency.

Importance of social relations as a key element for maintaining a good state of mind and health

It has been generally noted that people living in institutions have a poorer level of health and a lower rate of social relations.[4] This leads to a poorer quality of life and higher levels of anxiety and depression in people living in institutions (Liu et al., 2018; Otero et al., 2006), and therefore poorer levels of mental health (Drageset et al., 2015; Even-Zohar, 2014). When entering a centre, people leave their homes, their social networks and their living habits. This fact alone can already have an impact on their state of mind.

Dementia is currently the most prevalent neurodegenerative disease and the main cause of dependency in people over 65 years of age. Dementia affects around 5-8% of the world's population over the age of 60 and this percentage figure increases progressively with age and with a clear prevalence in females. Recent population studies in Spain show that between 5.5-5.8% of people over 65 suffer from this pathology and between 8.5-9.4% of those over 70. Forecasts indicate that in 2030 there will be 74.7 million people with dementia worldwide and there will be 131.5 million people affected by some form of dementia in 2050, compared to 46.8 million people with dementia in 2015. Studies indicate higher rates of dementia in women. The Alzheimer Europe Report noted that the incidence of women with dementia in Spain in 2018 was double that of men (580,758 women compared to 271,984 men).

Women are additionally more likely to live in residential centres than men; while women spend 94% of their time with the disease in residential care, men spend 60%. Many of the people living in residential care homes also have cognitive problems (Alzheimer's and other neurodegenerative diseases).

This does not imply, however, that no action can be taken to improve quality of life. For example, significant improvements in the psychological well-being of residents of institutionalised facilities occur when they participate in intergenerational and/or community activities outside the residence (Chipps & Jarvis, 2016).

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[3] It should be remembered that the official data only shows people in residential care homes and does not distinguish between people living in other models of institutionalised LTC (e.g. supervised flats).

[4] In fact, among non-institutionalised elderly people, it can be seen how having a partner or children cushions the feeling of loneliness, a dynamic that is not significant for those living in institutionalised settings (Prieto-Flores et al., 2011).

Types of residential facilities

Residential facilities could be classified according to the people they serve, dependent or not, but the profile of people who attend a residential facility without requiring assistance with daily life activities is increasingly lower, as age is closely associated with dependency and, additionally, the greater the need for help, the more likely they are to live in a residential facility.

Three main types of residential institutions can be identified in the scientific literature and these will be described below: residential centres for the elderly, nursing homes and sheltered housing or serviced flats.

Residential centres for the elderly

Residences in Spain, comparable to residential care (or residential aged care facilities), are permanent or temporary residential institutions for people who have limitations in performing daily life activities. Internationally, they tend to be private and take in a small number of people (20 or less), while in Spain they can be public, private, belonging to non-profit or privately managed public entities, with a number of residents varying from 10 to 200 users.

Analysing the reasons that lead to admission to a nursing home has not yet been widely studied in Spain, but there is a certain consensus with international evidence. Therefore, variables such as older age, the existence of physical or mental pathologies (or the need for constant, supervised pharmacological treatment), marital status (widowed or single) and low income or living in an urban environment multiply the likelihood of admission (Ayuso et al., 2010; Jamieson et al., 2019; Lillo-Crespo & Riquelme, 2018; Zueras & Ajenjo Cosp, 2010).

The possibility of choosing where to grow old and defining care profiles according to needs and interests facilitates the maintenance of a positive mental health status and can contribute to increasing quality of life (Wilkinson et al., 2012). But it should be noted that while this is common-sense reasoning, most studies are not properly randomised controlled experiments and it is therefore difficult to extrapolate causality or to claim that causality is not due to other factors.

Nursing homes: personal and health services

Next are the equivalent in Spain of nursing or assisted living homes, known here as *residencias asistidas*. They provide a wide range of personal and health services and are decidedly medical in nature, including a 24-hour nursing service. Most of them are focused on rehabilitation processes after hospitalisation, although they provide a wide range of services. Staying in these facilities can therefore range from temporary (after which the person returns to their home or residence) to permanent, depending on their physical or mental state. Thus, for example, they are the usual residence for people requiring a high degree of supervision, such as those suffering from moderate or severe cognitive impairment.

One remarkable aspect of these institutions is that, unsurprisingly, they reduce the number of referrals to hospital emergencies or hospitalisations. By having an integrated health care service, they allow more effective monitoring of elderly people with high degrees of dependency, compared to people with lower dependency but residing in institutions without medical follow-up, where health care is provided in primary care centres (Calvo et al., 2018). This is due to the fact that in care homes with a doctor on staff, continuous care, medication supervision and even the decision to transfer to hospital is made by this professional at the centre and not by primary care.

The evidence is mostly descriptive and correlational, although several studies apply some type of multivariate model. Most of the studies reviewed in this field are interested in the quality of life of the people living there, with a special focus on the prevalence of state of mind disorders, especially depression. But few studies employ random samples and few take into account the state of the person on admission. With moderate or severe degrees of dependency, these residents tend to have greater physical and cognitive impairment and, therefore, a lower overall quality of life (Buckinx et al., 2016).

Following along these lines, dependency and interaction with other people are related to a greater presence of depressive symptoms, while greater satisfaction with self-determination is tied to better adaptation to the institution and lower levels of depression (Ferrand et al., 2019; Park et al., 2012).

Following along these lines, the literature lacks a certain analysis of the spaces and architectural context of residential institutions, which tend to be quite similar to the hospital environment (long corridors, uniform layouts, etc.) and aimed at the simultaneous care of dozens of people. Thus, the more medicalised and hospital-like the environment, the lower the person's satisfaction and perception of quality of life (Kelley-Gillespie, 2012).

Trends in residential care are increasingly shifting towards a "home" model, including small living units and activities that are more in line with daily life in any home.

Sheltered housing or serviced housing

In the middle ground between these residential facilities and self-managed communities are sheltered housing (public in nature) and serviced flats (tending to be private in nature), both of which are comparable to retirement housing or sheltered housing. These are small functional homes in which a few self-sufficient people live together in a normalised manner on a partially self-managed basis. They do not have medical or health care services, only room and board. Some are private and more similar to a resort, with exclusive services such as laundry, daily cleaning, concierge, maintenance, care services (doctor, nurse, psychologist, 24-hour emergency care, physiotherapist and personal trainer) and leisure, social and cultural activities. They are in fact high-cost luxury flats.

They are home to relatively independent elderly people who, for various reasons, no longer wish to remain in their own homes or wish to enjoy a series of additional services in their own community (such as a dining room, laundry, etc.). These institutions therefore have flats or private rooms and these are combined with a large number of common areas and services available to residents. In the UK, they are known as HOOP (Housing Options for Older People). In Spain, they have barely been developed in certain municipalities, with limitations such as the total number of cohabitants, which must not exceed 10.

The literature is rather scarce in this field, although the most relevant research is robust and well elaborated. From this, it can be determined that if no effort is made in this type of facility to generate meaningful relationships among residents or to provide other types of emotional support, there is a greater likelihood of requiring mental health services (Park et al., 2012).

In the absence of any explicit endeavours at community vibrancy, these types of facilities show a reduction in leisure activities undertaken by elderly people compared to those undertaken prior to the move. It is therefore questionable whether this type of institution meets the social and leisure needs of the elderly (Knecht-Sabres et al., 2020).

On the other hand, depression rates are significantly reduced, especially among people with severe functional disabilities, if a kind of social commitment to the facility is activated and co-resident relationships are increased (Jang et al., 2014).

> *Depression rates are significantly reduced, especially among people with severe functional disabilities, if a kind of social commitment to the facility is activated and co-resident relationships are increased*

Chapter 5

Residential loneliness and new living options

Although the evidence clearly shows the preference of the elderly to remain in their homes, several studies question whether this choice is based on a fully conscious and informed decision or whether it is due to a lack of resources that make other housing alternatives possible during the last stages of life (Fernández-Carro, 2016), especially when people live alone, without a close relational circle, in situations of dependency or in homes that present serious accessibility problems.

There is a clear trend towards the growth of single-person households in developed societies, including those made up of the elderly. In fact, figures from the INE's Continuous Household Survey (ECH by its Spanish acronym) show that although single-person households comprising people under 65 years of age increased by 3.7% between 2014 and 2019, those comprising an older adult increased by almost three times as much (10.6%).

This situation poses a challenge for the quality of life of older adults, both in financial and social terms. Firstly because, although living alone does not necessarily mean feeling lonely, it does increase the risk of unwanted loneliness (Yanguas et al., 2018a).

Social relationships are an important part of quality of life throughout life as well as in old age. The subjective feeling of loneliness is not so much determined by something objective, such as the frequency of contacts, but rather by something subjective, such as satisfaction with these relationships. Loneliness results from a lack of social relationships and support and the perception that one's social needs are not as expected.

Loneliness has been linked to poorer health, limited social ties and poorer overall quality of life, and loneliness has also been shown to affect certain population groups more than others, such as the elderly, migrants, widowed people and caregivers (Pinazo-Hernandis, 2020a).

The experience of loneliness is not exclusive to the elderly and occurs throughout the life cycle, but it is accentuated by losses, ranging from relational losses (of the working circle after retirement, of friends or partners due to death or severe dependency, of neighbours due to moving house, etc.), losses of vision or mobility, or losses of reference spaces due to urban changes, gentrification and the closure of neighbourhood shops, etc. All these factors can lead to isolation and a sense of belonging crisis that can lead to serious negative consequences on mental and physical health. Indeed, the effect of loneliness is often compared to that of smoking 15 cigarettes a day or being obese, with real and perceived social isolation being associated with an increased risk of early mortality. The meta-analytic review by Holt-Lustad et al. (2015) aimed to establish the overall relative magnitude of social isolation and loneliness and examine possible moderators based on a literature search of previously published scientific studies. Social deficits were more predictive of death in people with an average age under 65, and the influence of both objective and subjective social isolation on mortality risk is generally comparable to well-established mortality risk factors (obesity, smoking, etc.).

The consequences of feeling socially isolated are increasingly recognised and proven, especially the link between loneliness, depression and the onset of cardiovascular problems, although the mechanism that causes this causal relationship is still unknown (Courtin & Knapp, 2017; Yanguas et al., 2018b). Several studies suggest that it may be an increase in cortisol (stress hormone), which effects both mental health – as it leads lonely people to find daily activities more stressful than those with a more active social life, and to focus more on negative thoughts and perceptions – and physical health, as it causes chronic inflammation that affects the immune system and favours the onset of other diseases (Cacioppo & Patrick, 2008).

In general, the evidence that emerges from the literature analysed is that the more extensive a person's network of relationships, the better their state of mind and health and, therefore, the greater their perception of quality of life (Brown et al., 2015). This fact has led to the emergence of increasingly more resources and programmes that combat unwanted loneliness and work towards creating and maintaining meaningful social relationships (Pinazo-Hernandis, 2020b).

New options for living together to be developed

Many people enjoy living alone, but for others it entails risks and expenses that are difficult to bear. Living alone is more expensive and less secure. There are several initiatives (mostly private) responding to these situations that are aimed at bringing together people who want to live with others, people who have a home and are looking for someone to share it with, whether they are young (such as *Viure i Conviure*[5]), only women (*Convive mujer*[6]) or with other elderly people (*Hogar y Café*[7]). The basic premise of these types of programmes is that they help people to live together and provide accommodation at lower costs than the housing market, in addition to the many psychological and social benefits for both generations.

Another proposal is the creation of self-managed living units, also known as "cohousing"[8]. This model in Spain is not as recent as one might imagine (the first national cohousing was set up 20 years ago), but the model is highly developed and dates back to more than 50 years in Northern Europe and the USA. Implicit in the strict concept of cohousing is the desire to grow old while integrated into the environment, for which a community of friends or acquaintances usually work together to design from scratch the architectural context and define the tasks and functions to be performed there. The design of the cohousing project looks at both the external environment and interior spaces, which should be as similar as possible to a home (in terms of spaces, sizes, furniture, etc.), and the performance of daily life activities (Martínez, 2013). Research shows cohousing as a possible alternative to classic residences, although there is very little literature comparing it with other types of LTC.

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[5] www.ajuntament.barcelona.cat/personesgrans/ca/canal/programa-viure-i-conviure.

[6] http://fundacionaliciayguillermo.com/convive-mujer/.

[7] https://www.fundacionpilares.org/hacemos/atencion-domicilio-entorno/hogar-cafe/.

[8] Although it can be observed in the literature that the concepts of "cohousing" and "collaborative housing", "self-managed communities" or "co-residences" are used as synonyms, these latter terms can imply other forms of community organisation that are not those intended to be presented in this section on cohousing. There is also a distinction in the literature between cohousing as a specific form of co-living, a concept that would refer to dwellings that combine private spaces with community spaces and services, with the explicit aim of promoting social contact and building a community (Shafique, 2018).

Conclusions

Long-life societies

Societies are becoming increasingly long-life, with life expectancy increasing in all countries, including Spain (83.3 years).

Population ageing poses a challenge to societies: in Spain in 2050, there will be 16,000,000 people over the age of 65, equal to 33% of the population. This fact calls for planning in the provision of long-term care and a rethinking of the care model.

There is a wide range of types of long-term care facilities: alternative residential facilities to the family home, those providing specialised and medicalised care, end-of-life care facilities, rehabilitation centres, care centres for people with disabilities, etc. There are few resources in general focusing on facilities providing care for the elderly and few of the facilities are public. There is a need to improve and expand the network of resources and to evaluate their effectiveness.

Need for long-term care for longer periods of time

According to the World Health Organisation, long-term care is the system of actions carried out by informal caregivers (family, friends or neighbours), professionals (health, social, etc.) or both to ensure that a person who is unable to perform daily life activities can independently maintain the best possible quality of life, in accordance with their individual preferences and with the highest possible degree of independence, autonomy, participation, self-fulfilment and human dignity.

Respect for human rights must always be present: it must be ensured that all people can age with dignity and security.

We can mention various places for providing long-term care: home care, which can be provided by a family or professional caregiver, or care in residential settings. Apart from the various resources and models of long-term care, the fact is that a growing number of people are going to require it and for increasingly longer periods of time.

The population is generally unaware of existing long-term care resources and the various residential models.

Long-term care differs fundamentally from acute care and health interventions in that its purpose is not to cure or heal an illness. It aims to promote the highest possible quality of life; to minimise, restore or compensate for loss of physical and/or mental functioning; to enable the dependent person to achieve and maintain as optimal a level of functioning as possible; to enable people to live as independently as possible; to help people perform essential daily life tasks, and, finally, to maintain limited levels of function, health, mental and social well-being to the maximum extent possible.

Formal caregivers are providers of care who are paid for their services and are associated with an organised service system, such as governmental organisations, non-governmental organisations and for-profit organisations. In addition, they are professionally qualified for the practice of care and include health and social care professionals (nursing, medicine, psychology, social work, physiotherapy, occupational therapy, geriatricians, etc.), providing personal care, health care and home care services.

Informal caregivers are people who provide care without receiving financial compensation for this task, lack the formal training to provide care and belong to the close circle of the dependent person. This is the case of members of the extended/nuclear family, neighbours and friends who become involved in care activities and care needs and help the dependent person on a regular and continuous basis, commonly throughout the day. Informal caregivers are usually family members, often a woman – wife or daughter – aged between 45-65 years, with no or part-time employment and with a low educational, socio-economic level. Care provision is also usually provided in the home of the dependent person on a daily, continuous and intensive basis (more than 40 hours per week) and it includes various types of support (personal care and housework, emotional support, etc.). This care is usually provided by a single caregiver for several years. Informal caregiving has been conceptualised as a stressful life event (caregiver burden syndrome) that, alongside its chronicity and unpredictability in terms of when its conclusion, is associated with negative repercussions on the physical and psychological well-being of the informal caregiver. Caregiving leads to negative consequences, but it also has positive consequences and major benefits.

Various long-term care models, different resources according to Autonomous Communities

The older a person, the higher the degree of dependency and functional loss and the greater the need for care. Residential centres are necessary as a resource for long-term care. The profile of the majority of people living in residential homes is that of an adult with a high level of dependency, over 85 years of age, female and mostly with cognitive impairment. But there is limited knowledge of the residential sector. On the one hand, there is no national body to represent, unite, support or supervise them. On the other hand, regulations are regional and display major differences among Autonomous Communities (in staff ratio, types of professionals, characteristics of the services provided, etc.).

Lack of coordination of services and social and health care levels

There is a lack of public resources and almost no relationship between public and private resources. If we take into account the minimum levels of coverage recommended by the World Health Organisation (5% of the population over 65 years of age), there is currently a deficit of 65,000-80,000 places in residential centres.

The health and social spheres function in various ways and have different, unshared databases. No socio-health coordination exists and people have to make a pilgrimage among disconnected services.

Family, state, business and the third sector are the cornerstones of service provision, although one of these, the family, is more important in Spain: 80% of dependent persons receive informal care. The burden of care has traditionally fallen on families and especially on women, often as sole caregivers.

Investment in care training is needed. There is a need for support and training for informal caregivers and also for continuing specialised training for professional caregivers (not only on specific aspects of care, but also on good treatment and respect).

Ageing in place

People prefer to age in the place where they have lived all their lives and where they have their relational ties and supports. Lack of social connection is directly related to emotional problems (anxiety, depression, stress, etc.) and also cardiovascular and cognitive health problems.

But for people to continue to live at home, these homes must adapt to the ageing of their members and environments must become facilitative, bringing services closer to home. Many people need continuous assistance to perform various daily life activities (dressing, feeding, moving around, etc.). There is a lack of home care resources and a lack of coordination among existing resources.

COVID-19

The SARS-CoV-2 pandemic has had a greater impact on the most vulnerable people (dependent elderly people, people with chronic illnesses, etc.) and it has highlighted the need to improve long-term care, the need to provide more funding for services and the need to dignify the care profession with better salaries and greater recognition.

Lockdown, the closure of centres and the cessation of therapeutic and socialisation activities have meant a change in the usual routines of residential and day care centres and other long-term care services. In the coming months, we will be able to observe the impact on quality of life, the negative cognitive, psychological and functional evaluations and the return of diseases, especially in the case of people with cognitive impairment.

Future challenges *in long-term care*

1

Caregiving societies

At some point in our lives, all of us have been cared for, will be cared for or will have to care for others. Care is the responsibility of everyone and must become a civic duty and obligation. We need to review long-term care and rethink the world of care.

Addressing loneliness is also a challenge for caregiving societies. Informing about the importance of care and maintaining social relationships as a mechanism to combat unwanted loneliness and democratising and visualising existing strategies to increase the relational network of the elderly can contribute enormously to increasing their quality of life while at the same time implying financial savings in the field of health care.

2

Intergenerational solidarity

There is a need to improve the integration and community involvement of all people and thereby increase intergenerational cohesion and solidarity.

The pandemic has once again revealed something that we are particularly interested in highlighting on these pages: the need for societies and communities to be inclusive of all ages and generations, not only for reasons of solidarity, equity or social justice, but also in order to achieve stronger, more capable and more liveable communities. The current pandemic has reminded us of the problems that we suffer as a community and that must be solved as a community.

Care puts at stake not only the viability of present life, but also its capacity to endure into the future. And it is precisely intergenerational care that has as its purpose that of paying specific attention to the connection between people's well-being and the passage of time: the more generations living together at any given time, the more likely and urgent is intergenerational care. When we do this, we are committing ourselves to the future of cared-for generations, linked over time to caregiving generations.

3

Common regulations and increased funding and types of resources

Spain has 384,251 residential places in 5,567 centres distributed unevenly throughout its territory.

Taking into account a lack of resources and residential places, around 12,000 new places need to be created each year. This would truly address long-term care and simultaneously create jobs in the care sector.

Health, social and economic policies related to care must be improved given the fact of increasing demographic demand and the state of the residential sector (inadequate number of places and few specialised centres).

4

Social and health care coordination

The integration of public policies from various sectors around common objectives is both necessary and complex. The adoption of a socio-health coordination model presents clear opportunities when it comes to caring for people. On the one hand, a comprehensive, integrated approach in which care services revolve around people and not the other way around. On the other hand, by optimising public and private resources for the care of people requiring long-term care.

It is necessary to coordinate the various agents involved in care (families, proximity services at home, primary care centres and hospitals, residential centres, voluntary work, neighbourhood network, etc.).

We need to create new services in the areas where people live, around their homes, and to redefine and improve the various support and care services, thereby transforming home care (not only in terms of content, but also in terms of intensity). We also need to focus innovatively and create a wide range of services between the margins of independent living at home and residential care homes for the elderly in situations of dependency.

These different services must provide improved, more intensive home care (more professionally qualified, able to provide greater complex care and more hours of dedication per person) and include services that are common in other countries, such as serviced flats, assisted living or those that need to be designed (innovation is also a key element in this sector). These facilities should be smaller in size, with greater personalisation of care and more versatility in terms of providing help and accompaniment to people.

Good care costs more money and we need better working conditions, a greater variety of services and professionals dedicated to this.

Care needs to be the focus of public policies. Otherwise, we are heading for collapse. At various points in our lives, we will be cared for, we will need to be cared for or we will have to care for others.

Autonomy and dependence are not opposites, nor are they mutually exclusive terms. How can we guarantee the greatest possible autonomy (in terms of action, decision-making, etc.) for ageing people? Vulnerability is part of our lives.

Focusing on people

5

Services must revolve around people, with an integral and integrating approach from a one-stop service that, on the one hand, has the capacity to act quickly in situations of greater vulnerability and, on the other hand, can prevent, care for and improve quality of life. Promoting an active life is linked to delaying situations of dependency.

Person-centred care is based on a respect for rights and decisions about people's lives. The focus is on participation and defending personal autonomy for as long as possible. The person is an agent in elaborating his or her life and care plan.

Ageing in place

6

Improving environments (accessibility, friendliness) makes it easier for people to live their old age where they desire. The more extensive a person's network of contacts, the better their state of mind, their state of health and their perception of quality of life.

Advances in telemedicine will enable remote monitoring of chronic and acute pathologies, diagnosis, monitoring, self-care and home treatment and permanence.

Diversity

7

The group of people over the age of 65 is not a homogeneous group. As age increases, the differences between people become greater, resulting in very different ways of ageing. Public policies must take these differences into account when it comes to designing resources and programmes. More resources are needed (more day centres, more residential centres, more home help services, more telecare), but also more variety of provision. The rise and development of new ways of living together (cohousing, shared housing, etc.) is a fact and must be taken into account by managers at a local level.

The perspective of gender must also be included in addressing long-term care. There are more elderly women in vulnerable situations and there are also more women who are informal and professional caregivers.

Evaluation and research

8

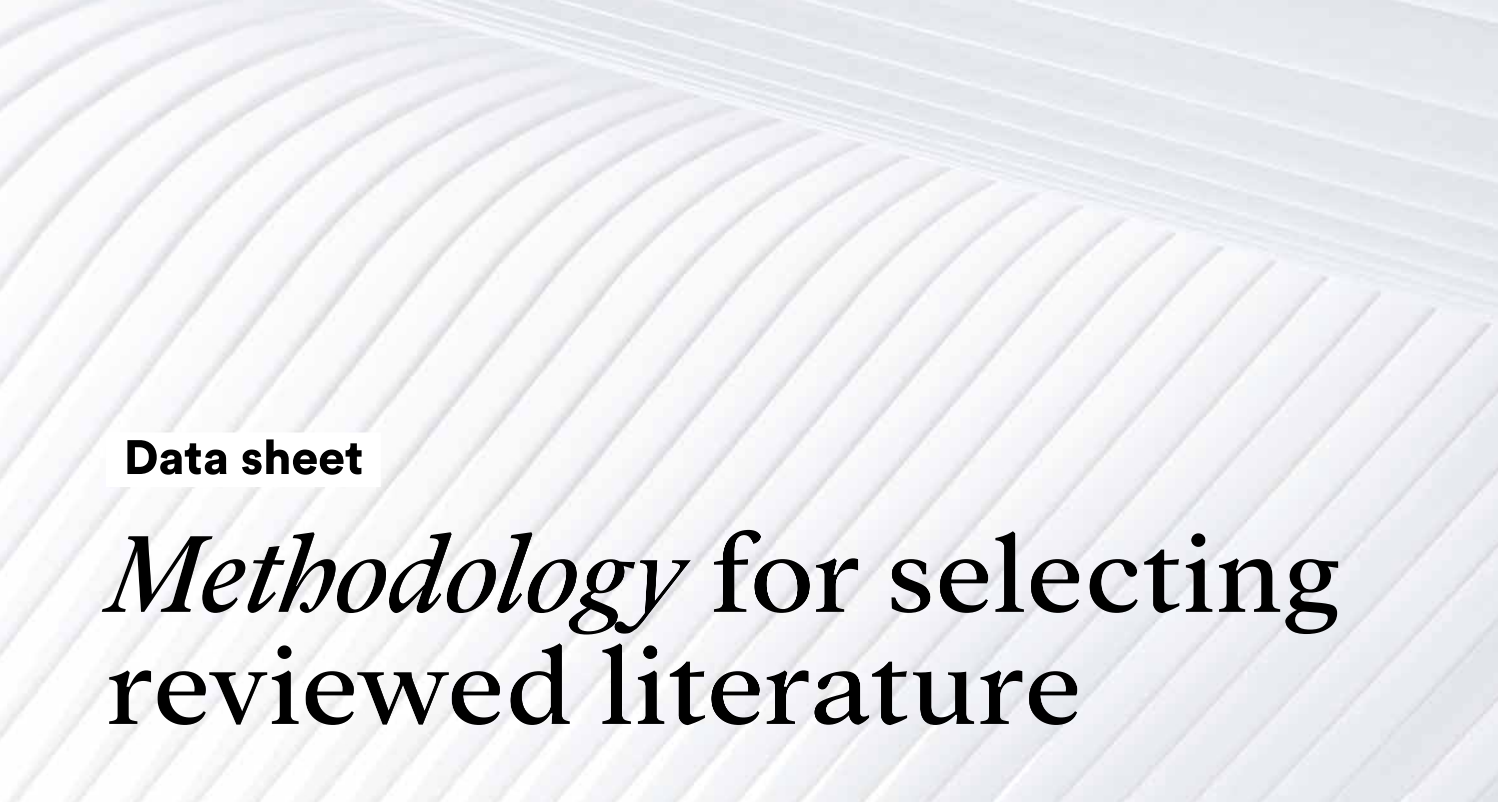
One of the clear conclusions that can be drawn from this report is the need for social diagnoses to understand the reality and needs expressed by people in need of long-term care and to evaluate projects, programmes and resources.

There is a need for longitudinal studies at a state level to improve resources and adapt them to changing needs.

The commitment to address LTC in long-life societies should be more preventive than it is at present, at least in Mediterranean countries. Expanding information on existing resources and putting the person at the centre of the decision-making process would help to increase satisfaction and quality of life, disassociating these from the availability of a family or financial resources. These factors currently have a clear implication when it comes to designing programmes aimed at extending publicly funded home care for the elderly with disabilities in most of Europe.

There is still therefore a need in Spain to shed light on the sector in order to accurately assess how many people receive informal care at home, how many are housed in residential facilities and how many choose new forms of cohabitation. Despite the opacity, it can nonetheless be noted that the existing resources are limited and few of these are public.

There is still therefore a need in Spain to shed light on the sector in order to accurately assess how many people receive informal care at home, how many are housed in residential facilities and how many choose new forms of cohabitation



Data sheet

Methodology for selecting reviewed literature

Systematic review of literature and selection based on expert judgement

This study summarises the findings located in 111 documents that analyse LTC in the elderly. Of these, 62 were obtained by systematically searching for the specialised literature, 35 from a search of studies based on expert judgement and 14 correspond to reports produced by foundations or organisations specialising in this field. This section explains the procedure that was followed.

A systematic review of the specialised literature on the models of LTC and cohabitation of the elderly was initially proposed. This review was based on the Campbell Collaboration methodology, which establishes an objective, transparent and systematic literature search protocol.

Firstly, the working team jointly agreed on the scope that the review would take with The Social Observatory of the “la Caixa” Foundation, as well as its inclusion criteria. It was therefore decided not to limit the literature to a specific geographical or temporal scope and to include both academic studies and those produced by international organisations or foundations. The main models on which the search was based were defined, such as residential care and home care, including various care alternatives or different models of cohabitation in each of these areas.

At this point, the keywords for the search were also determined. Concepts such as well-being, quality of life, social relations, mortality, benefits and costs were considered as main results of the LTC models. These were combined with a variety of models (home care, day centres, residential centre, cohousing, etc.) and concepts such as “the elderly”, “seniors”, etc.[9] The search included keywords in Spanish and English. Any research analysing case studies; cross-sectional, experimental or quasi-experimental studies; interventions (randomised or not); qualitative studies, or article reviews were taken into account, provided they referred to the models included in the review.

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[9] The search included keywords in English and Spanish: *long-term care settings/facilities, LTC, nursing care/home, assisted living, continuing-care, life-care, residential aged-care, day-care home, dependency, care, senior centre, retirement home, respite care [a “short break” is used in some countries to refer to a respite], older adults, senior, nonagenarian, octogenarian, centenarian, ageing/aging, old people, elderly people, pensioner, elder, cohousing, e-health, loneliness, isolation, health women vulnerability, social frailty, ageism, age stereotypes, self-perception of aging, pandemic, COVID-19, coronavirus, severe acute respiratory syndrome, SARS-CoV.*

Figure 1.

The various Boolean search engines were built based on these words and the Scopus[10] database was used, thereby initiating the search stage of the studies, both in English and Spanish. Given the large number of results, it was decided to limit the search to the last decade and then include the research that, after reading the studies, was relevant to this study and had been published before 2010. As Figure 1 shows, a total of 293 papers were identified that met the specified criteria after searching with the keywords. Duplicates were then eliminated and the reports to be analysed were selected from this resulting research on the basis of their title and abstract. From the 92 studies that passed this selection, the team read each document in its entirety and finally selected the 62 documents that make up the systematic review. These were classified in a database including information on the sample used, the country or geographical area referred to, the research question, the methodology, a score based on the Maryland Scientific Method Scale (SMS)[11] or the main findings.

After conducting this systematic search and evaluating the results, it was detected that those obtaining a better score had not been carried out in Spain and were not fully representative of the Spanish reality. As the aim of the study was to gather the state of this issue at both an international and national level, it was considered necessary to extend the resulting selection with studies conducted by third sector entities and organisations that displayed a greater emphasis on providing LTC to the elderly in Spain. After reviewing the initial structure of the report on the basis of the evidence found, The Social Observatory of the “la Caixa” Foundation and the work team therefore decided that a more profound, extensive study of some areas was required.

A new complementary search of the literature was therefore carried out based on expert criteria. In this second phase, 35 studies were identified and a total of 14 reports from public entities and foundations were also included in order to conduct as exhaustive a review as possible.

[10] See: https://www.scopus.com/.

[11] The SMS is a scale from 1 to 5 that ranks research – especially evaluations – according to the robustness of the methodology used. The SMS ranking criteria range from 1 (study where causality cannot be identified) to 5 (randomised experiments). The main criterion for examining the robustness of the methodology is based on how the method deals with selection problems. This hierarchy is not absolute and a cross-sectional study may provide better evidence than a study with a complex, poorly executed methodology, or without sufficient data. Given that many of the studies located by this search failed to score on the SMS scale, it was purely considered as a guide and not as a triage element for selecting the research analysed.

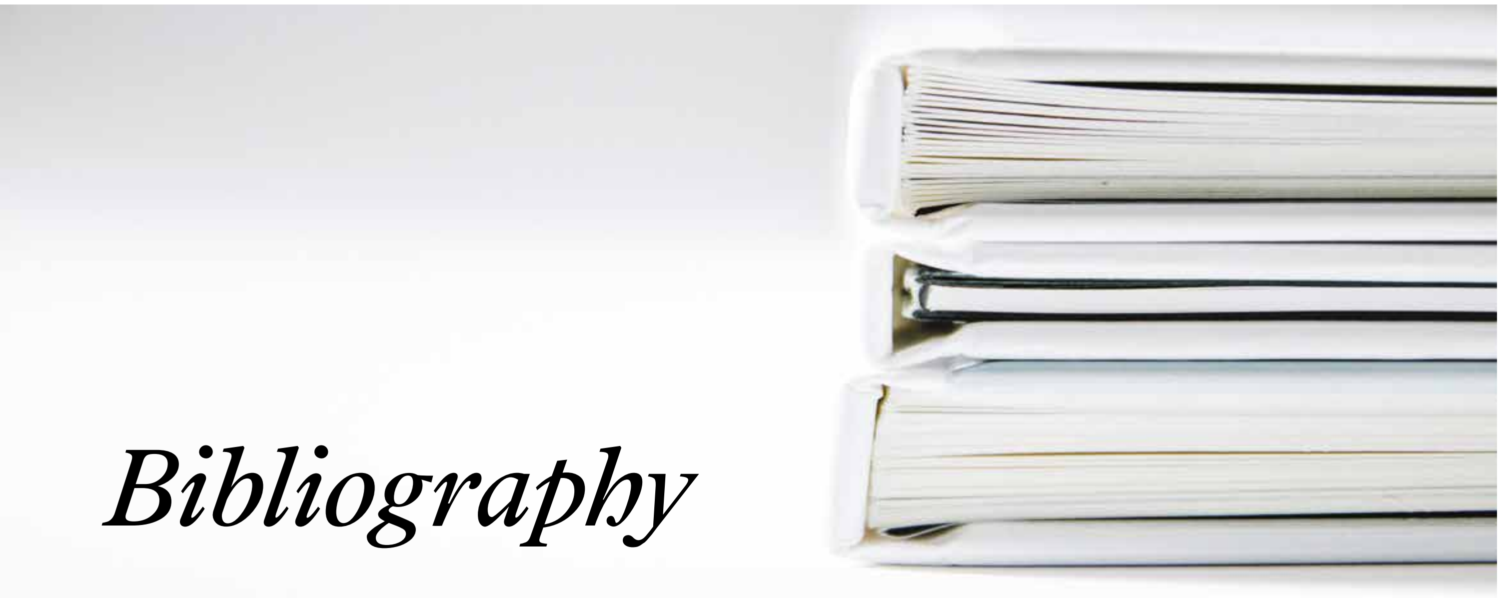
From the 111 studies and reports that passed these two selection phases, a summary of the studies included in this review was conducted and this includes the main results of the current literature specialising in the field of LTC.

Characteristics of the evidence found

One of the main difficulties identified in the literature review lies in the fact that a significant number of the studies and reports analysed fail to provide an accurate description of care models, especially in relation to the architectural context or the services associated with providing one or other LTC model. In fact, the definition of dependency, care or caregivers is not even based on standardised criteria. Very different and even divergent definitions can therefore be found under the same concept. This makes comparison between various research studies particularly difficult and is compounded by the fact that a variety of concepts are used in different countries to describe the same type of care facilities.

At the methodological level, most studies rely on surveys to assess both characteristics of study participants – e.g. degree of dependency/autonomy – and outcomes – e.g. level of satisfaction of people using services or programmes. In many cases, these are self-report measures that are often performed by the same centre or service.

As mentioned in the assessment based on the SMS scale, very few studies are based on randomised controlled trials (RCTs) and most use unsophisticated research designs or quantitative methods. People in various care models are not compared in the same research, so it is difficult to ascertain if the results obtained are due to the model in question or to the specific characteristics of the people using that model. It is therefore observational evidence in most cases. This calls for caution when it comes to drawing conclusions from the use of each of these models.



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