



**POLITECNICO**  
MILANO 1863

DIPARTIMENTO DI ARCHITETTURA  
E STUDI URBANI



LPS – Laboratorio di Politiche Sociali

# **Ageing in place in different care regimes. The role of care arrangements and the implications for the quality of life and social isolation of frail older people**

Giuliana Costa (Politecnico di Milano)  
Maria Gabriella Melchiorre (INRCA)  
Marco Arlotti (Politecnico di Milano)

DASU  
Working Papers  
n. 03/2020 (LPS.10)  
ISSN 2281-6283



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### **Abstract**

*The aim of this paper is to address how care arrangements shape the conditions of older people living at home and the main implications for them as far as quality of life and social isolation are concerned. We will consider the complex mix of actors involved in providing care for older people, focusing in particular on the crucial role played by the state, family/informal networks and private services in a comparative perspective and with specific attention to the Italian case. Due to the fact that the literature about the relationship between care arrangements, quality of life and social isolation is still limited and dispersed in a plurality of studies and scientific contributions, we propose here the main evidence of such relationship, acknowledging that further investigation is needed.*

### **Key words**

*Ageing in place, Care arrangements, Quality of life, Social isolation, Welfare: Housing and Public Services*

### **Short bio of authors**

#### *Giuliana Costa*

*Giuliana Costa Ph.D. is an Associate Professor in Sociology at the Polytechnic of Milan. Her main research interests are connected to local welfare policies, to the development of long-term care policies and to housing welfare programs and projects. She is currently studying cohabitation models within social policies. She participates in several research projects funded by the European Union, the Italian Government and other research agencies.*

*giuliana.costa@polimi.it*

#### *Maria Gabriella Melchiorre*

*Maria Gabriella Melchiorre, MS, collaborated with the University of Ancona, Department of Economic Sociology, from 1989 to 1997 on several national and international research projects on migrants and care policies for the family. Since 1997 she has been a researcher at the Centre for Socio-Economic Research on Ageing, INRCA-IRCCS of Ancona, working on many European projects on the social aspects of family caregiving, long-term care, elder abuse, migrant care workers, multi-morbidity, frailty and eHealth.*

*M.Melchiorre@inrca.it*

#### *Marco Arlotti*

*Marco Arlotti, Ph.D. in Economic Sociology, is currently a researcher at the Polytechnic of Milan. His research interests include comparative analysis of social policies, with a particular attention to social assistance schemes and policies for dependent elderly people. At the international level, he has participated as national expert in several research projects funded by the European Union, as well as by other public and private institutions.*

*marco.arlotti@polimi.it*

DASU Working Papers – LPS

*Ageing in place in different care regimes. The role of care arrangements and the implications for the quality of life and social isolation of frail older people* | Costa, Melchiorre, Arlotti



LPS – Laboratorio di Politiche Sociali

<http://www.lps.polimi.it/>

*How to cite this working paper:*

Costa, G., Melchiorre, M.G., Arlotti, M. (2020), *Ageing in place in different care regimes. The role of care arrangements and the implications for the quality of life and social isolation of frail older people*, n. 03/2020 (LPS.10).



## 1. Introduction<sup>1</sup>

Until few decades ago, older people in need of care were supported exclusively by women in the family entourage, be them spouses, daughters, daughters in law or sisters, informally and without pay. With the increase of women's participation in the labour market and the "getting older" of societies, many countries have created some public provisions in the field of elderly care and devoted economic resources to senior citizens (Kröger, Sipilä, 2005). The welfare states of post-industrial society have incorporated care needs into their scope, at least to a certain extent, recognizing them as specific risks. Social rights for both elderly citizens to receive care and family members to give care have been institutionalized (see Knijn, Kremer, 1997; Frericks et al., 2014)<sup>2</sup>.

This incorporation followed different patterns and paces. As a matter of fact, care policy differentiation in European countries reflects institutional developments that have taken place in different historical phases. Path-dependent processes determined how the current configuration of care regimes has been shaped and structured (Ranci, Pavolini, 2013).

As a large body of research has shown (Eurofamcare, 2006; Fujisawa, Colombo, 2009), care in Europe remains a "family matter" as most care work is provided by family members; families continue to have a pivotal role in care arrangements even when public or private services are available (Costa, 2012). Families are the most important providers of care, but welfare state policies may support or supplement them. Other actors have joined the family and the state in the care function of elderly people, leading to the expansion of those who may have responsibility for care provision: organizations and individuals that provide care within a market or quasi-market logic. To account for the pluralization of care sources and the different composition of these sources in different contexts, scholars followed up and further developed traditional conceptualizations of welfare states by characterizing "care regimes" in Europe (Anttonen, Sipilä, 1996; Munday, 1996; Kautto, 2002; Bettio, Plantenga, 2008; Keck, 2008). Each "care regime" is distinguished by a specific and structured mix of actors of the care system—State, family, market, voluntary sector—responsible for care in old age and by the institutional formation of care arrangements, in other words how and by whom care needs are tackled in society.

Care regimes function as "social joins" ensuring complementarity between economic and demographic institutions and processes (Bettio, Plantenga, 2008): on the one hand, they change together, but on the other, care regimes also act as independent incentive structures that contribute to the definition of family economic organization models such as women's labour market participation and fertility (Bettio, Plantega, 2008). Care regime typologies set up "significant dimensions for comparative analysis of the institutional design of policies (eligibility criteria, levels and types of support) and the underlying cultural values embedded within distinct mixtures of state and family responsibilities" (Theobald, Luppi 2018, 3). In this sense, care regimes account for structural dimensions in societies.

In this paper we will discuss how the different components of care regimes—the State, the family and informal networks, the market—operate in covering the care needs of elderly people living at home, analysing the role of each component separately in order to disentangle their functions in generating various care arrangements. Each paragraph presents the main aspects to be taken into consideration when depicting the structural dimensions of care regimes in Europe. A special focus will be placed on Italy's specific care regime, even if it will be in some way depicted in other parts of this work being part of the Southern European countries.

Within each paragraph we identify the possible connections between care regime characteristics and the analytical dimensions at the core of the In-Age project, i.e. quality of life, social isolation and loneliness in old age. As pointed out in the literature (see Arlotti et al., 2020a), quality of life is a complex analytical concept, in which different dimensions are included: from more objective aspects related to

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<sup>1</sup> This paper has been written in the context of the IN-AGE project. The project is supported by Fondazione Cariplo, grant n° 2017-0941 ([http://www.lps.polimi.it/?page\\_id=2829](http://www.lps.polimi.it/?page_id=2829)).

<sup>2</sup> More generally, provision of social services become a central topic in distinguishing welfare states (Alber, 1995).

individual factors to the characteristics of the context in which people concretely live as well as to the role played by subjective perceptions and expectations. Similarly, also the two concepts of social isolation and loneliness entail considering both the structural and objective features of isolation in terms of absence of relations and emotional attachments, and how people actually perceive their condition according to individual expectations and prominent social norms.

Considering that the literature focusing specifically on the relationship between care regime characteristics, quality of life, isolation and loneliness in old age is still limited and dispersed in a plurality of studies and scientific contributions, in this paper our attempt will be only to find clues of such relationship. For this reason, our work can only be considered as partial and in progress.

## 2. The role of the State

### 2.1. Positioning the State in the care mix

Even if the most important actor in caring for elderly people in Europe is the family, the role of the State in structurally designing the care mix among different actors is at the core of care regime conceptualization. According to Pavolini and Ranci (2013), when analysing long-term care policies in Europe, care regimes “are to be considered as institutional forms codifying particular social entitlements (i.e., the social right to receive care in the case of need) and related forms of service provision or support (including coverage of costs of care)” (Pavolini, Ranci, 2013, 12). The main structural features of “care regimes” that are connected to the role of the State are based on two specific analytical dimensions: the way in which care responsibilities are implicitly or explicitly attributed to families and the type of role assumed by public actors in terms of interventions and services mobilized in the coverage of care needs.

For the first dimension, although care needs are mainly covered by informal networks and intergenerational solidarities in all Europe, their role tends to be differentiated among countries depending on how care obligations are legally defined (Haber Kern, Szydlik, 2010), and therefore on how they are set up into public regulations. In Northern European countries, the coverage of care needs tends to be mostly framed as a universalistic-individual right, which implies a limited attribution of care responsibilities to families and intergenerational solidarities. In Continental and in Southern European countries, care responsibilities are in the hands of families but within different family solidarities and public policy relationships. In the case of continental countries, such type of relationship is framed by a principle of “active subsidiarity”, which means that intergenerational solidarities are actively supported by public policies (through cash transfers or the delivering of in-kind services). In Southern European countries, substantial care responsibilities are assigned to families without adequate public support, putting them in a sort of “passive subsidiarity” role (Kazepov, 2010; Ranci, Pavolini, 2013).

Many scholars proposed different classifications of “care regimes” analysing the interplay between family and public responsibilities towards care needs in different European societies (Anttonen, Sipilä, 1996; Munday, 1996; Kautto 2002; Bettio, Plantenga, 2008) and proposing groupings of countries based on the mix of care provisions including social care, leave arrangements and financial support. One of the most interesting classifications combines instead two dimensions—the degree of legally defined attribution of care responsibilities to the families and the role played by public policies—identifying three main care regimes at the European level based on intergenerational responsibilities (Saraceno and Keck 2010), identifying in this sense conditions and processes of:

- 1) *de-familisation*, in which the presence of a wide and articulated network of home and residential services and the individualization of social rights implies a significant reduction of family responsibilities, typical of Northern European countries;
- 2) *supported familialism*, in which the presence of family care obligations is, however, supported both through financial transfers and in-kind services, typical of continental European countries;

3) *familialism by default*, where a broad attribution (also legally defined) of care responsibilities for families is not adequately supported by public policies, due also to a residual implementation of in-kind services limited only to the most serious cases, typical of Southern European countries.

The interplay between family and public care responsibilities fed studies about the existence or not of crowding-out effects between them. The underlying question of these studies is: “does mutual solidarity within families decrease with growing public services?”. The majority of cross-country comparisons showed that there are complementary rather than substitutive effects (van Oorschot, Arts, 2005; Motel-Klingebiel et al., 2005). Other studies claimed that there is even a crowding-in effect between public and family support because disburdening caregivers improves and balances family relationships, which, in turn, has a positive impact on family caring capacity (Künemund, Rein, 1999; Lewinter, 2003). More recently, Verbakel (2018) showed that generous formal long-term care provisions crowd out intensive caregiving, but at the same time encourage more people to provide (some) informal care more frequently.

## 2.2. Public provisions in care arrangements

The second structural analytical dimension connected to the role of the State that configures different care regimes is related to how formal care provisions are mobilized by public actors to cope with care needs. Bettio and Plantega (2008) classify them into three different categories: time off, money and services. In this regard, the relevant aspects considered are the presence and main characteristics of the institutional schemes aimed at recognizing and promoting the reconciliation of care and work (e.g. parental leaves, career breaks, reduction of working time, etc.) and the type and amount of public interventions, both in the form of financial aid and in-kind services provided to support the care needs of dependent older people (Bettio, Plantega 2008; Saraceno, Keck, 2010).

The need to reconcile care and work activities brings into care regimes the issue of the “dual focus” of specific policies towards care (Saraceno 2010): the person in need of care and the caregivers. The intervention of the State to support the latter in their caregiving activities is related in this case to the fact that people, mainly women, are frequently squeezed (not necessarily in severe forms) between caring and working for the market. According to Colombo et al. (2011), almost 50% of carers are in paid employment in Europe, ranging from 31% in Greece to 78% in the United Kingdom. “Time based” caregiver policies aim to allow families to choose their own preferable care arrangement and differ in care regimes. Other dimensions of family care have partly been addressed by policies recognizing “care work” with pay and social security (Frericks et al., 2014).

To what regards the type and amount of public interventions in the form of financial aid and in-kind services, “care regimes” tend to be strongly differentiated according to the overall degree of care needs in old-age coverage assured through in-kind services, be they provided at home or in residential settings, and through cash for care allowances. In other words, “care regimes” tend to be distributed along a continuum related to the overall “generosity level” of their welfare state policies towards care, which tends to replicate to some extent the well-known differences affecting welfare regimes in Europe as a whole (Esping-Andersen, 1990; Ferrera, 1996; Kazepov, 2010). Generosity in most classifications is related to the amount of in-kind provisions and their entitlement structure. Moreover, considering the impact on care needs, a crucial issue concerns also the professional standards as well as the intensity of care actually provided, from which, consequently, derives how much care responsibilities tend to be covered by public intervention and how much, instead, they stay in the hands of the families (Saraceno 2016).

### 2.1.1. Public provisions in Italian care arrangements

In general terms, Italy is considered in the literature as a paradigmatic example of a “familialism by default” model (Saraceno, Keck, 2010). Indeed, as we have seen in the previous section, a broad

attribution of care responsibilities to families is not adequately supported by public policies, due also to a residual implementation of in-kind services, frequently limited to the most serious cases. More specifically, Italian long-term care policies are articulated into two main sectors of intervention, cash allowances and services in kind, which are not coordinated with each other and are subject to different eligibility criteria. The main sector of intervention is related to the implementation of cash allowances, and in particular, to the so-called “Indennità di accompagnamento” (hereafter IdA, which in English can be translated as “National Attendance Allowance”), which has a national regulation.

The IdA is a universal allowance (520.29 euros per month in 2020) that is not means-tested and is available to citizens certified as totally dependent. The right to this benefit is officially ensured to those who are totally disabled. It is an unconditional cash-for-care scheme as beneficiaries can freely spend cash benefits without any type of restriction and control.

Services in-kind include instead mainly residential and home services, provided either by regional governments or local authorities, two policy arenas that in most regions are not integrated; home-based health services are organized by regional health agencies, whereas social services are provided by the municipalities (Costa, 2013). They are characterised by marked geographical inequalities (Ascoli, Pavolini, 2015) due to the lack of central regulation and inadequate financial support for the local development of extensive in-kind services.

Given these conditions, IdA constitutes the mainstay of the Italian long-term care system. In 2016, the government spent around 19 billion euros (1.13% of GDP) on providing care to meet the needs of frail older people (NNA, 2017). Around 80% of public funds are used to finance the IdA measure, to support family caring tasks or to hire paid informal carers, which fosters “the development of a widespread system of informal caregivers” with around 800,000 caregivers for 2.3 million people in need of long-term care (Longo, Notarnicola, 2018). In Italy, cash benefit schemes thus represent the main pillar of the long-term care system (Ilinca et al., 2015), and Italian family carers are fundamental for the implementation of care services and ensuring their continuity (Melchiorre et al., 2013).

As far as in-kind services are concerned, public social-health spending has progressively decreased in Italy over the recent years, also as a result of the restrictions concerning the resources of the territorial entities (introduced by the Stability Pact until 2015), whereas private expenditure appears to have increased or at least remain at very high levels. (Montemurro, Petrella, 2016). Thus, under-investment in public in-kind services, including home care, has led to a context where often the economic burden of the growing and complex care needs of elderly people falls on households (Ilinca et al., 2015).

### **2.3. Elders living in place, quality of life and social isolation: the role of the State**

In the literature on care regimes, particular analytical attention is placed on their impact on specific socio-economic dimensions (Bettio, Platenga 2008; Ranci, Pavolini, 2015), such as the reduction of the care burden for family caregivers, the working conditions of care workers and gender imbalances in care. At the same time, more limited is the attention placed on the impact and the relation of care regimes with the two dimensions specifically addressed within the IN-AGE research project, i.e. quality of life and social isolation. Indeed, these dimensions tend to be more considered in relation to the caregivers' condition (see Verbakel, 2014; Wagner, Brandt, 2015), while the effect on the side of frail older people is rather neglected.

Given the scarce literature available on this topic, we will refer to the impact on quality of life and social isolation of the elderly in the European context considering the relation with welfare regimes as a whole (Esping-Andersen, 1990). We will thus focus more specifically on the impact of welfare regimes on both the dimensions at an “aggregate” level on the one hand; and, on the other, on the degree of inequality existing in the distribution of quality of life and social isolation between the different social groups in each country.

As far as the first aspect is concerned, several studies show that the quality of life of older people tends to be higher particularly in countries in which welfare states are more developed in terms of interventions and services supply (e.g. Scandinavian countries), while it tends to be lower in those countries (e.g. liberal countries and south-European countries) where policies are more residual (Motel-

Klingebiel et al., 2009). Similarly, the same differentiation, albeit with an inverse sign, sees a lower level of loneliness and social isolation in those countries in which welfare states are more developed (Nyqvist et al., 2018).

In this respect, it is important to consider that according to the literature, specific individual factors (e.g. health conditions, economic conditions, social relations, etc.) play a crucial role in shaping the degree of perceived quality of life as well as of social isolation (Arlotti et al., 2020a). For instance, having more financial resources undoubtedly makes participation in cultural and leisure activities more feasible, which positively stimulates the sense of well-being and autonomy as well as the possibility of social interactions. Moreover, higher levels of education and employment success can contribute to a better “control” and evaluation of one's own life, and therefore, to a higher level of quality of life (Niedzwiedz et al., 2014). However, such individual factors are clearly shaped also by the redistributive role played by welfare policies, which in turn affect the quality of life and social isolation of older people.

Considering, instead, the impact of the welfare regimes on the level of quality of life and social isolation across different social classes in each country, the literature seems to reach more ambivalent findings. For example, with reference to the quality of life, some studies have found that the effect of welfare state policies on the degree of differentiation in the level of quality of life in old age among different social classes within each specific country seems to be less significant than the impact that welfare states have at the “aggregate” level comparing different countries (Motel-Klingebiel et al., 2009). Other studies instead point out that national contexts characterized by more generous welfare states tend to present not only higher levels of quality of life, but also narrower socioeconomic inequalities in the level of quality of life in old age among different social groups (Niedzwiedz et al., 2014).

### 3. Informal caregiving

#### 3.1. Informal caregiving in care arrangements

Informal caregivers and carers are non-professionals—relatives, friends, neighbours, volunteers—who “take care” of a person with chronic illness, disability or other long-lasting health conditions in need of in-kind support. The cared-for are mainly older people, generally spouses, parents, parents-in-law and grand-parents, but also friends. Informal caregivers provide unpaid long-term support and services at home or in other places without a formalized contract on the basis of personal motivations and social norms (Colombo et al., 2011; OECD, 2017; Barbabella et al., 2018). They provide help in the accomplishment of basic activities of daily living (e.g. going to the toilet, dressing, eating) or of instrumental activities (e.g. preparing meals, housekeeping, transportation) (Eurocarers, 2017; Di Rosa et al., 2018). In the following we will provide some numbers and discuss some crucial elements regarding different kinds of informal care across Europe.

Informal care represents a great part, about 80%, of the total long-term care provision in Europe. (Hoffmann, Rodrigues, 2010; Zigante, 2018). Its weight in the care-mix is, however, different from country to country. In 2015, across OECD countries the share of people aged 50 and over providing care to a dependent relative or friend was 13% (OECD, 2017), with different intensity. Sweden, Switzerland, Denmark and the Netherlands showed the lowest rates, being countries where the formal care sector is well-developed and public coverage is comprehensive. According to Eurofound, 12% of carers in Europe provide care at least weekly to elderly aged 75 and over (2017).

Verbakel (2018) found that the prevalence rates of informal caregiving are much higher and vary substantially among European countries. She labelled as *informal caregivers* those who answered affirmatively to the question of whether they spend any time looking after or giving help to family members, friends, neighbours or others because of long-term physical or mental illness, disability or problems related to old age. In Europe, proportions are as low as 20% to as high as 44%. Informal caregiving for at least 11 hours a week (i.e. intensive caregiving) ranged instead from 4% to 11%. From the geographical point of view, her data showed opposing patterns regarding the prevalence of informal caregivers and the prevalence of intensive caregivers. The Nordic countries have relatively many



caregivers, but few intensive caregivers. Other authors arrive to the same conclusions in analysing the width and the intensity of care across Europe (Albertini et al., 2007; Brandt, 2013).

Informal carers represent thus a fundamental resource in tackling the care needs of older people, especially in Southern and Eastern European countries, characterized by a low provision of public services. In Northern European countries, where a wide range of well-established formal LTC services have been developed, families are there but less intensively (Barbabella et al., 2018; European Commission, 2018). Southern European countries present stronger family ties, with social/cultural norms establishing family responsibilities and intergenerational support (Bremer, 2017), and thus with more support exchange within households (Chiatti et al., 2013a).

In Europe, informal care to elderly people is traditionally provided by spouses, adult children and grandchildren (Bolin et al., 2008; Bonsang, 2009; Van Houtven, Norton, 2008) or by co-residing adults (Weaver et al., 2014). Older people who live alone receive on average about 50% of their informal care from children, with the remaining 50% is provided by other relatives and friends (Dobrescu, Iskhakov, 2014; Bonollo, 2018). Literature indicates that on average 60% of informal carers are women (OECD, 2017)—spouses, adult daughters and daughters-in-law—ranging from 70% in Poland and Portugal, to 62.4% in Italy, and to 45.6% in Sweden. Around two thirds of informal caregivers take care of a parent (mainly younger carers aged 50-65 years) or a spouse (mainly carers aged 65 and over) (Ibid). A great share of informal care is provided by people who are older than standard retirement age (Colombo et al., 2011). Usually, when there is a spouse, he or she is the primary caregiver (Eurocarers, 2017), alone or with support from children and friends. Other relatives are mainly complementary in caregiving tasks. In particular, findings from the EUROFAMCARE study (Lamura et al., 2008) indicate that the informal support coming from other family members, including friends and neighbours, is relevant in helping to find information and easing the access to social care services, especially in the Mediterranean countries where case manager professionals are missing in most public policies.

The absence of family support is hard for most people in need of care. Childless older people often experience a “care gap” when becoming frail and needing hard and intense support, especially when formal support and services are not available (e.g. in Southern European countries) (Deindi, Brandt, 2017), even if they have a functioning compensative support network (e.g. extended family, friends and neighbours). Conversely, relatives, when present, come up to provide stronger support and assistance when unexpected life events (e.g. the loss of a relative, a fall) occur in the life of an older person, alleviating consequences of the event itself (Thoits, 2011). In some studies, falling has been found to have both implications on the victim's life and overall health and on the life of respective relatives (Pin, Spini, 2016). The relatives of fallers seem indeed more strongly involved in social support and burdened after a fall, especially in case of older people with complex needs or dementia (Kuzuya et al., 2006), what in turn has long-term overall effects on the provided support (Pin, Spini, 2016).

In recent years the presence of friends as carers has increased in the personal networks of older people, sometimes also acting as a significant safety net (Suanet et al., 2013). Friends and neighbours play an appreciable role in caring for older people in several European countries (e.g. 19% of respondents in Ireland, 15% in Belgium and Denmark, 14% in Sweden, European average 11%) and medium/low in others (e.g. 8% in Italy and 5% in Poland) (Bettio, Verashchagina 2012; Drożdżak et al., 2013). Neighbours and friends take up the role of primary caregivers when family members cannot support the older relative (Barbabella et al., 2018; Jacobs et al., 2016).

Another piece of informal care is provided under the supervision of formal volunteering associations and bodies: this unpaid care work may represent a considerable element in the care mix in between the family, the State and private service providers (Drożdżak et al., 2013). According to a Eurobarometer (2010) survey, Europeans consider solidarity and humanitarian aid (34%) and healthcare (24%) as fields where volunteering can play an important role. Collaboration from volunteers usually covers specific tasks: psychosocial support, assistance with social activities, prevention of accidents in the home, information on available and useful services, provision of “respite opportunities” for the primary caregivers (family, friend or neighbour) (Seabright, 2013). Volunteering involves around 10% of the population in Italy whereas higher percentages are reported in Northern European countries (Principi et al., 2014).

### 3.1.1. Informal caregiving in Italian care arrangements

In Italy, families are crucial providers of LTC support to frail older people and informal care remains the first caring choice when compared with home and residential care services (Drożdżak et al., 2013). As already highlighted above, indeed the Italian LTC system has traditionally (and implicitly) relied on the role of the family, both as informal unpaid care given by family caregivers (especially wives and daughters) to a dependent elderly family member, and as family private spending for direct assistance. On the whole, about 9% of the Italian adult population is involved in unpaid caring activities, and most of the support is concentrated in domestic activities (NNA, 2015).

According to Istat (2017), among the elderly (65+) with a severe reduction of autonomy in personal care activities, over one in four older people can trust on a solid social support network, and over half of the elderly refer to have in the family the help of a person or to have support from home care services. Nevertheless, 58% refer they have insufficient support, and thus would like to receive more help, especially the poorest ones. It is to highlight that 30% of the elderly (about four million) have serious difficulties in performing IADL, and that 47% are aged 75 years and over. Even if most elderly do have social support, 24% who live alone refer that they have no help at all (Istat, 2018). In a recent study focusing on elderly 75+, it emerged that 86% of them are helped by non-cohabitant family members; only 14% do not receive any care (Melchiorre, 2019).

The Italian elderly receive help and support, but as Europeans they are also providers: it is estimated that 1 million and 700 thousand (12.8%) of them take care of family/non-family members with health problems (or due to the aging process) at least once a week. One out of five caregivers is thus old, and almost two-thirds of elderly caregivers are aged 65-74 years (Istat, 2017).

### 3.2. Elders living in place, quality of life and social isolation: the role of informal care

Elderly care needs are mostly met by informal carers (family and friends) in all care regimes. They remain the “backbone” of the assistance provided to most dependent older people (Hoffmann, Rodrigues 2010; Chiatti et al., 2013a; Di Rosa et al., 2018) even in contexts with a high level of public services in in-kind provisions. Their caregiving represents also the main factor ensuring the sustainability of care systems (Tomini et al., 2016). In this respect, some evidence highlights how the presence of the family can influence individuals’ opportunities and risks along their life course, their resilience to adverse conditions, and also their quality of life and wellbeing, especially with the frailty and disability that occur in older age (Ferraro et al., 2009; Chiatti et al., 2013a).

As known, family caregiving can be provided both in a context of hyper-proximity due to co-residence and in arrangements where the elderly live alone in their own residence or elsewhere. Family carers often live with the cared-for persons and provide assistance for personal and home care, emotional support and care management (O’Leary et al., 2010). According to the Report “Better at home” (The Live-in Care Hub, 2016), older people who are supported by live-in carers are much more likely to eat and drink what they prefer than those living in residential institutions/facilities. This positively influences their quality of life, lowering the risks of urinary infections and falls. Family carers are a crucial determinant in maintaining the quality of life of older people with dementia, also by preventing their institutionalization (Farina et al., 2017). However, some studies highlight that the support of children is beneficial to older relatives with regard to their quality of life when it is provided at a moderate level, i.e. neither too frequently nor too occasionally (Katz, 2009). When the elderly indeed receive “too much” support, they can feel a sense of guilt as well as a sense of loss of autonomy (especially in case of on-hands care). These negative feelings seem to have an impact on their perceived quality of life and well-being (Lowenstein et al., 2007). Moreover, co-residence in a relative’s home is not accepted when older people consider this arrangement as reducing both their own and their children’s independence (Olsberg, Winters, 2005), and also when they don’t want to be a burden on the family (Gott et al., 2004).

The caring function of families is very important also for reducing the isolation of the elderly, for preventing institutionalization and for enabling people to remain at home and age in place. The presence and not sporadic help of family members (including spouses) for preparing meals, doing housework and providing transportation, seems thus indispensable for the elderly ageing at home (Dupuis-Blanchard et al., 2015). Otherwise, staying at home could lead to isolation, with older people perceiving residential care as a more positive solution facilitating social integration (Fernández-Carro, 2016). In this sense, there is evidence that the quality of social relationships may contrast social isolation more than the number of ties, and this suggests that a “few solid relationships” may be more beneficial than “many ties of poor quality” (Theodore, 2017). Living arrangements and quality of social relationships greatly affect also loneliness (Stojanovic et al., 2017).

Barriers to providing care, such as geographical distance from the cared-for, time constraints e.g. due to a paid job, costs for travelling to the home of the care recipient, and the lack of carer skills (Broese van Groenou, De Boer, 2016) all negatively affect the quality of care and thus the quality of life of the elderly. Conversely, the possibility for working carers to have flexible work conditions and paid care leaves allowing them to provide care while working part-time (European Commission, 2016; OECD, 2017), as well as training opportunities, have beneficial effects on their skills and quality of life and care. Especially training opportunities for caregivers on specific competencies (e.g. disease-specific skills, symptoms/emergency situations management) can indeed promote both their wellbeing and better communication with the cared-for, resulting in quality care and added value for ageing in place (Eurocarers, 2016). A recent review indicated that training interventions were effective in improving carer knowledge and communication skills; however, more specific and targeted interventions seem needed in order to have beneficial effects on the quality of life of both carers and the cared for (Morris et al., 2018). In this respect, a literature review by Rand (2012) explored the evidence of a possible link between the wellbeing of carers and that of care recipients, and identified factors affecting their associated quality of life. Significant positive correlations were found between carers and the cared for with regard to mental and physical health (Myaskovsky et al., 2005), stress and depression (Vangel et al., 2011). Moreover, dyads with lower related quality of life were associated with higher carer burden, whereas dyads with a high combined quality of life were linked with lower carer burden (Bergstrom et al., 2011). Also, the relationship mutuality-reciprocity seems a significant predictor of life satisfaction for both stroke survivors and respective spousal caregivers (Ostwald et al., 2009). Finally, financial strain was linked with lower quality of life for both caregiver and the cared for (Morgan et al., 2011).

A decline in co-residence or in geographical proximity of older people with their children (in addition to increased participation of women in the labour market) have reduced the availability, ability, propensity and willingness of potential informal family carers to provide assistance for the elderly (European Commission, 2018), thus worsening their isolation. Some studies suggested that the geographic distance between parents and their children (between generations) is a key determinant of contacts between them. In this respect, proximity affects both the nature and frequency of contacts (Lin, Rogerson, 1995), and consequently both the isolation and loneliness of the elderly. In fact, “older people who see their children once a month or less are twice as likely to feel lonely than those who see their children every day” (WRVS, 2012). Proximity is thus important and can determine important choices in the elderly’s life. They are less likely to move elsewhere, e.g. to a care institution, when their children are “near”. According to van der Pers and colleagues (2015) for instance, widowed people are more likely to move elsewhere when their children were living at a distance of more than 40 kilometres.

Another aspect to be highlighted in the relationship between informal care and loneliness regards the possible isolation of caregivers. Although informal care can improve the quality of life of older people, informal caregivers need to be supported because—but not only—frailty can occur both in the older cared for and in caregivers (Lambotte et al., 2017). Potential isolation or loneliness of family carers when managing stressful situations as those connected to their own health and social problems should not be underestimated, especially when they are full-time carers of people suffering from cognitive impairments or dementia (Reinhard et al., 2008; Chiatti et al., 2013a). The isolation and loneliness of family carers seem furthermore amplified by a negative perception of available formal care services for the cared-for (Wagner, 2018).

## 4. The private market

### 4.1. Private provisions and care arrangements

Home care in Europe is usually funded from a mix of sources, including private payments, and a great variety of home care providers is available, including private not-for-profit or private for-profit organizations (Genet et al., 2011). Private not-for-profit providers include organizations composed of volunteers, or managed/owned by religious or civil society bodies (e.g. cooperatives); private for-profit providers include organizations that are privately owned or controlled by stakeholders (Rodrigues et al., 2012). The “marketization” of care, i.e. the de-institutionalization and privatization with the introduction of market competition logics, take place through “vertical subsidiarity” (e.g. by moving provision/financing of services from central to regional/municipal government) or through “horizontal subsidiarity” (e.g. by “outsourcing of services” to non-governmental organizations) (Deusdad et al., 2016). Marketization is also implemented through the diffusion of privately paid personal assistants who care for elderly people at home.

#### 4.1.1. Privately paid formal home care services

Private spending represents a significant part of total long-term care (LTC) costs, but is often difficult to “detect” (European Commission, 2016). Data on LTC are seldom collected merging and publishing public and private care. For instance, the OECD Health Statistics regarding in particular LTC resources and utilization, refer to people receiving LTC at home publicly or privately financed (OECD, 2018). Private expenditure for health and social care, which is collected under the System of Health Accounts, seems to exclude important out-of-pocket payments by informal carers (European Commission, 2016). Moreover, for many countries only aggregate data for both private residential and home care are collected (Rodrigues et al., 2012) and it is important to highlight that significant under-reporting exists, given that some private spending remains outside of any public system (Muir, 2017) and is thus not captured by any statistics.

Despite these limits, some data about private spending for LTC are available. On the whole, private sources are estimated to be around 30% of current health expenditure in European Member States through out-of-pocket payments, be they co-payments or private health insurance premiums (European Commission, 2016). The “marketization process” of LTC is particularly strong in Northern and Central Europe, but it has also been introduced in Eastern and Southern Europe (Deusdad et al., 2016). There is evidence (according to merged data on both residential and home care for some countries) that the Third sector of private not-for-profit providers is traditionally preeminent in Austria, Germany and France, as well as in the Netherlands, Italy and Belgium, whereas private for-profit organizations are stronger in England and Spain (Rodrigues et al., 2012), although Germany shows also a notable rate of for-profit organizations (Riedel et al., 2016).

Private providers have, in general, an important role across Europe, especially in the provision of home-based care, less in institutional settings (Riedel et al., 2016; Van Eenoo et al., 2015). Private provision of LTC services, in particular community care, is mainly provided by not-for-profit organizations in most countries, although the number of private for-profit organizations is increasing. On the contrary, health and nursing care is mostly covered by public financing, whereas domestic care (e.g. cleaning and cooking), is often privately covered, even if some countries such as the Netherlands and Sweden offer comprehensive LTC. The private care work force consists of a minority of nurses and a majority of personal care workers with low skills. Wages are relatively low, especially for those without formal training; care workers are mainly female, and in some European member states like Italy, mostly foreign-born (European Commission, 2016).

Which contextual and structural factors lead to the use of private care services? We know that the “institutional design, coverage, and intensity of public support provision influence the extent to which households resort to the market” (Albertini, Pavolini, 2017). In countries where the number of hours of

public home care provided by the social protection system is limited, older people with severe or chronic care needs who have no family or friends providing unpaid care, have to rely, at least to a certain extent, on assistance “in place” from private care services. The condition for paying for care services, especially where they are relatively expensive, is that savings are available (Muir, 2017). Household income seems indeed a crucial factor for accessing and paying for formal care services that are affordable on the market. In this respect, cash benefits which are distributed to elderly people in need of care (e.g. vouchers for recipients as “prepaid entitlements” to buy care instead of benefits-in-kind) increased particularly the importance of private providers and market-oriented care services (Genet et al., 2011).

#### *4.1.2. Privately paid foreign care assistants*

In many countries, especially in Southern European, the gap between the expanding demand of care services, the modest public LTC service provision and the reduced capacity of families to care on a long-term basis has largely been filled by low-cost care work provided by single individuals, resulting in the emergence of private care markets made up of foreign migrants (Costa, 2013). Since the 90’s we have been witnessing a global movement of care workers involved in the provision of essential assistance to the elderly in many States (Anderson, 2012). According to some authors, the extensive engagement of migrant care workers led to a “transition from a ‘family’ to a ‘migrant in the family’ model” (Bettio et al. 2006, p. 272). In fact, care is also provided by migrant care workers who are privately hired and employed on an individual basis directly by the older person or by his or her family to carry out in-house personal care, housekeeping and other burdening tasks. They are often female, living-in or working many hours per day, and in many cases irregularly employed (Barbabella et al., 2018; Muir, 2017). Ageing in place, in this case, entails a triangular caring relationship that involves the frail older person, the migrant care worker and the family caregiver (Di Rosa et al., 2018).

Some years ago, a study of the International Labour Organization estimated 150.3 million migrant workers in the world, of which 11.5 million were migrant domestic workers, mostly women (ILO, 2015). In such a context, migrant care workers (MCWs) have emerged as an important solution for ageing in place because they meet elderly care needs at home (Da Roit, Weicht, 2013).

The increasing number of MCWs represents a relevant trend in many countries around the globe (Barbabella et al., 2018). In European countries their number increased greatly especially in the period 1999–2009 (Lamura et al., 2013; Barbabella et al., 2016), more than doubling their presence in some countries (e.g. Belgium, Denmark, Greece, Ireland, Portugal, and Sweden), and even more than quadrupling in Italy and Spain (Cangiano, 2014). MCWs have represented a crucial resource for decades mainly in family care-based systems (e.g. Greece, Italy, and Spain), whereas in countries such as France, Germany, and the UK, which are characterized by a mixed-services context (in-kind, allowances, informal care, and private market), their presence has increased significantly in more recent years (Nies et al., 2013; Pavolini, Ranci, 2008). The rate of paid foreign-born people among home-based caregivers of long-term care (that is who care for older people, people with disabilities, and children) is greater in Italy, Greece and Spain, respectively 90%, 75% and 68%, whereas it is between 10-15% in Germany, the Netherlands and Belgium (WHO, 2017).

The employment of MCWs is more extended in Mediterranean countries, where it is considered as a “normal” solution to manage the growing elder care challenge (Lamura et al., 2010). This pattern can be especially found in Southern countries (e.g. Italy, see section 2.1.1. and below) characterized by the existence of cash-for-care schemes for dependent elderly people and by a poor regulation of migration flows (Barbabella et al., 2016).

MCWs working in Europe usually come from Romania, Poland, Bulgaria, the Philippines and South America (Chiatti et al., 2013b). In most countries they are middle-aged women working part-time and with poor work conditions and low wages (Barbabella et al., 2016; WHO, 2017). Their presence however has also increased unregulated labour (Williams, 2010): less than 15% of home-based MCWs are indeed estimated to be formally employed.

#### *4.1.3. Private market care in Italian care arrangements*

As said above, statistical data about private spending on LTC are affected by several limits. Data for Italy also have the same limits as those collected at the European level because they are often spurious, combining both public and private expenditure. Some comprehensive findings show that household spending on "assistance for disabled persons and dependent elderly" was around 1.8 billion euros in 2013 (Montemurro, Petrella, 2016). More recent data (Rapaccini, Dallaglio, 2017) suggest that on the whole, great part of LTC costs amounting to 14.4 billion euro are borne directly on households, around 46% of total spending. Around 4.8 billion is spent by families that care for the elderly and dependent relatives (34% of total private spending). The families with dependent people (mainly but not only the elderly) are 1,758 million: 7% of the total. In 79% of cases, care is entrusted to family members without any external help. Only 21% of families use services and the average amount of their expenditure is 8,627 euros per year.

The most popular private service is given by personal assistants (the so called "badanti"), used by 11,5% of families with a dependent member and the average spending is 10,348 euro per year. Only 7,1% use formal carers, spending on average 5,756 euro; 2,3% use residential care spending 8,904 euro per year. According to a calculation on Istat data among the elderly 75+ living alone, the use of private personal assistants is quite widespread: 58% relied on them every day, 18% a few times a week (Melchiorre, 2019).

Regarding private home care, about 6% of the expenses incurred by the elderly living alone or in couples is for health services, a higher value compared to that of the general population (4.4%). With regard to the more general item of expenditure for "other goods and services" (e.g. costs for personal care, social assistance, including insurance and financial services) the expenses of the elderly living alone are lower than those of the elderly living with a spouse/partner (5.8% vs. 7.4%) (NNA, 2015). Moreover, 76% of financially weak families refer to have renounced (totally or partly) to acquiring private assistance services for older and dependent family members (Rapaccini, Dallaglio, 2017). Similarly, previous literature also indicated that only 27% of households were able to acquire professional home care (Ilinca et al., 2015).

According to available data, about a third of long-term care resources come from patients and families, both as an informal assistance value and as an out-of-pocket expense for in-kind and or insurance services (NNA, 2015). Italian private care organizations often do not operate within public regulations (Van Eenoo et al., 2015), although the strongest private providers "lobby for more integrated public purchasing processes" (Longo, Notarnicola, 2017).

## **4.2. Quality of life and social isolation of the elderly living in place: the role of the private market**

Regarding the impact of affordable private/paid home care services and their relation with quality of life and social isolation as addressed in the IN-AGE study, a first crucial aspect affecting these two dimensions is the cost of the services themselves. This is indeed often high, and elderly people cannot always pay for the services, especially if (family) savings are not available. It might thus be possible that the elderly do not purchase at least all of the care they need, with reduced quality of life as consequence (Muir, 2017). Of course, such a critical aspect can be significantly different across different social classes, affecting especially the elderly belonging to lower socio-economic classes.

Also, the opportunity for households to privately hire MCWs to support daily care tasks can have an important impact on the quality of life of the elderly (Melchiorre et al., 2014). If on the one hand this solution can allow the elderly cared-for to age in place and to be (and feel) less isolated while allowing many women caregivers to continue their professional career, on the other it raises some crucial issues indeed. For instance in some cases the relationship between foreign carers, cared-for older people and family carers may be hard to manage due to cultural/linguistic aspects. In such a context, older cared-for persons may also refuse the presence and the help of a foreign private assistant in their home, with negative effects on their own quality of life. Another crucial issue affecting the quality of life of the elderly

is that often MCWs are not adequately trained on caregiving and especially on carrying out particular nursing/personal care tasks (Barbabella et al., 2016; 2018). Their employment thus puts forward crucial issues about the quality of care provided. Care work is in fact not an unskilled job, as it requires several competences as well as patience and empathy. Unfortunately, the low skill level of MCWs frequently results in poorly qualified workers, and this further contributes to them being employed in the unregulated sector and within the grey market (Anderson, 2012). Interventions to support and train paid home carers could potentially improve the health-related quality of life and well-being of older home-care clients (Cooper et al., 2017).

## **5. Conclusions. Care arrangements, quality of life and social isolation of frail older people: an overview**

In this paper we have analysed and discussed how the State, family, informal networks and private market operate in covering the care needs of elderly people living at home in a comparative perspective and with specific focus on the Italian case.

We have seen that the concept of “care regimes” (Anttonen, Sipilä, 1996; Munday, 1996; Kautto, 2002; Bettio, Plantenga, 2008; Keck, 2008) is a crucial analytical tool through which it is possible to identify and disentangle the complex mix of actors responsible for care in old age. We have also seen how care regimes vary from country to country and how they affect the living conditions of the elderly ageing at home.

Furthermore, we have identified the possible connections and relationships between the main components of the care mix and the two analytical dimensions at the core of the In-Age project, i.e. quality of life and social isolation/loneliness among frail older people living at home.

Although the current literature is somewhat limited and mostly dispersed in a plurality of studies and scientific contributions, the goal of the literature review presented and discussed here has been to identify possible links among these dimensions for further empirical investigation.

Starting with the role of public policies, we have seen that a majority of studies clearly show that care policies complement rather than substitute family support (van Oorschot, Arts, 2005; Motel-Klingebiel et al., 2005). In other words, care policies support a better balance of family care responsibilities and improve the caring capacity of families (Künemund, Rein, 1999; Lewinter, 2003), particularly when the support is “generous” and delivered through in-kind services (cash for care transfers instead seem to imply passing the buck to families and strong gender imbalances). This in turn may have relevant implications on both the quality of life and the social isolation of elderly people living at home. Better conditions for caregivers may indeed have an indirect effect on frail older people. At the same time, and more directly, welfare policies can shape specific individual factors (for instance health conditions, economic conditions, etc.) that are crucial as well in determining the degree of perceived quality of life and social isolation among older people (Motel-Klingebiel et al., 2009; Nyqvist et al., 2018, Arlotti et al. 2020a).

As far as family and informal networks are concerned, we have seen that their role is crucial in all care regimes. In this respect, some evidence highlights how the presence of the family can deeply influence the resilience of older people to adverse conditions, as well as their quality of life and wellbeing (Ferraro et al., 2009; Chiatti et al., 2013a), supporting their ageing in place and lowering the risks of institutionalization. However, some studies also report a more ambiguous effect. For instance, the support of children seems beneficial to older relatives with regard to their quality of life only when it is provided at a moderate level, i.e. neither too frequently nor too occasionally (Katz, 2009). When the elderly indeed receive “too much” support, this can cause a sense of guilt as well as a sense of loss of autonomy (especially in case of on-hands care). These negative feelings seem to have an impact on the perceived quality of life and well-being of older people (Lowenstein et al., 2007).

Also for social relations, and especially for what concerns the perception that older people have about them, the role of families and informal networks is recognized in the literature as crucial in reducing the risk of isolation and loneliness. In this regard, a “few solid relationships” may be more beneficial than “many ties of poor quality” (Theodore, 2017). The nature and the frequency of family contacts is relevant

as well. Older people who see their children once a month or less have twice the risk of feeling lonely compared to those who see their children every day (WRVS, 2012).

Finally, regarding the impact and the relationship of private/paid home care services with quality of life and social isolation in old age, a first important aspect is that access to such services is strongly determined by economic conditions. In this sense, the possibility of expanding care support through access to the private market and consequently increasing the quality of life affects older people in different social classes very differently.

Similarly, being able to hire a care assistant directly, as in the case of migrant care workers, can have an important effect on the quality of life of the elderly (Melchiorre et al., 2014), but, again, this possibility is conditioned by strong socio-economic inequalities (Arlotti et al., 2020b). Furthermore, such a solution can allow the elderly to age in place and be (and feel) less isolated, but it also raises issues that can critically shape the conditions of older people, especially when the quality of care provided is low or the relationships tend to be problematic due to cultural/linguistic aspects.

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