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Informal Caregivers: is there a light at the end of the tunnel? An analysis of the Informal Caregiver Statute

Ester Coelho de Oliveira

Master in Political Economy

Supervisor:

Doctor Fátima Suleman, full professor

Iscte – Instituto Universitário de Lisboa

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Department of Political Economy

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## **Resumo**

A maioria dos cuidados prestados na Europa é assegurada por cuidadores informais. Contudo, a sua contribuição, fulcral para a sustentabilidade do setor dos cuidados, é presenteada com uma falta de apoios sociais. Depois de perderem ou abandonarem os seus empregos para cuidar de um familiar dependente, os cuidadores enfrentam a realidade inquietante de que, a partir desse momento, as suas carreiras ficam estagnadas, a sua autonomia pessoal e financeira roubada, e os seus problemas tornam-se invisíveis. É necessária ação legislativa para corrigir este desequilíbrio. Através da realização de entrevistas individuais a cuidadores informais e a um membro da sociedade civil, esta dissertação descreve as características sociodemográficas de um conjunto de cuidadores em Portugal, explora as suas perceções sobre o impacto do Estatuto do Cuidador Informal na sua vida pessoal e profissional, e identifica formas de ajuda social que na opinião dos cuidadores deveriam ser adotadas para reforçar o apoio. Os resultados revelam que os cuidadores tendem a ser mulheres com idade compreendida entre os 45-59 anos, com menos escolaridade e empregadas, que em muitos casos incorrem em custos de oportunidade. Relativamente à perceção da legislação, é de notar que a maioria desconhece a mesma e sublinha o impacto nulo do Estatuto. Os poucos que conhecem a legislação, manifestam o seu descontentamento e defendem um apoio social mais abrangente. Este estudo tem o mérito de dar visibilidade a este grupo, procurando informar e apoiar os decisores políticos a implementar políticas que considerem os desafios que os cuidadores enfrentam no seu dia-a-dia.

### **Palavras-chave**

Cuidadores Informais; cuidados a idosos; emprego; proteções sociais; estatuto do cuidador informal; Portugal.

### **Código JEL**

J83; O35.



## **Abstract**

The majority of care provided in Europe is performed by informal caregivers. However, their contribution, central to the sustainability of the care sector, is met with a lack of social support. After losing or giving up their jobs to care for a dependent family member, informal caregivers face the unsettling reality that from that point on, their careers are stalled, their personal and financial autonomy is taken away, and their problems are made invisible. Legislative action is crucial to address this imbalance. Through a series of individual interviews with informal caregivers and a member of civil society, this dissertation describes the sociodemographic characteristics of a group of informal caregivers in Portugal, explores their perceptions of the impact of the Informal Caregiver Statute on their personal and professional lives, and identifies forms of social aid that caregivers believe should be adopted to reinforce support. The results show that informal caregivers tend to be women between the ages of 45-59, with less education and employed, who often have to incur opportunity costs. Regarding legislation perception, it should be noted that the majority are unaware of it and emphasize that the Informal Caregiver Statute has had no impact on their lives. The few familiar with the legislation express their discontent and argue for more comprehensive social assistance. This study has the merit of giving visibility to this group, and seeks to support and inform policymakers to adopt and implement policies that consider the challenges that informal caregivers face in their daily lives.

### **Keywords**

Informal caregivers; eldercare; employment; gender; social protection; informal caregiver statute; Portugal.

### **JEL Code**

J83, O35.





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## CHAPTER 1

# Introduction

Although care work plays a crucial role in sustaining our capitalist market-based economies – as many feminist economists have theorized –, it was only in recent years that political actors have begun to understand how fundamental it is for their countries to adopt and implement policies that recognize care work, and those who do it, as pillars of the good functioning of whole societies. While the issue of care has been on the EU policy agenda since the 1980s – through recommendations, guidelines, and reports (José & Wall, 2004) –, and parliamentary debates in the Member States have become more frequent (Courtin et al., 2014), the concerns of those who provide care remain unheard. Seen by the public as peripheral members of society, these citizens live precarious lives, surviving off the help of whoever might reach their hand, and off scarce statal subsidies. Whether voluntary or involuntarily, these people carry on their backs the results of failed policies that do not ensure that they have the conditions to live a dignified and autonomous life while caring.

The motivation to conduct a dissertation on informal care in Portugal stems from two different observations. The first concerns the tendency for the number of informal caregivers to increase in the coming years, since an increasingly elderly population will always have higher levels of dependency due to a greater incidence of chronic diseases, making it more pressing for society to rely on forms of formal and informal care work (Ehrlich et al., 2020; Amaral et al., 2020; Fisher et al., 2021). This reliance is amplified in times of crisis, when the malfunctioning of care systems is highlighted (Eurocarers, 2021b). The COVID-19 pandemic serves as a stark example. Not only did it increase the care burden of caregivers, but it also forced new individuals into this role, as formal services were unable to respond to the challenge. In addition, the aggravation of unemployment and precariousness, together with multiple cuts in subsidies and social support, affected the purchasing power of the population, which now, more than ever, lacked the means to externalize care to formal institutions. This resulted in a huge shift of children and the elderly from the formal to the informal sphere of care (Soeiro et al., 2020). This shift not only demonstrates the importance of informal caregivers, who are preventing entire care systems from collapsing due to the increasing demand for long-term care (LTC) (Fisher et al., 2021), but also highlights the general underdevelopment of formal care infrastructures, and their unavailability to common citizens who cannot afford its costly prices. Hence, studying this group, which keeps gaining relevance worldwide, but continues to be ignored in the public policy arena is extremely relevant, for they will certainly have a role in shaping our future societies, and

how care is socialized in them. It should be noted that in Portugal, as in other Southern European countries, families constitute the core actor in the provision of care to elderly, disabled, and other people, while public provision is insufficient (Lopes, 2017; José, 2012; Adão e Silva, 2002).

The second motivation to conduct this dissertation stems from the fact that there has been an informational gap regarding the situation of Portuguese informal caregivers since 2019, with the adoption of Law No. 100/2019 (DRE, 2019a), which created the Informal Caregiver Statute (ICS). This Statute is particularly important since it represents a milestone in the recognition of informal caregivers and their work, consecrating them with rights and obligations. However, the extent of its impact, whether positive or negative, on caregivers' lives in light of their perceptions and knowledge of the law remains unmeasured, constituting a literature gap. In this way, it becomes imperative to evaluate just this, by analyzing caregivers' perceptions regarding their professional prospects, government support, and general social life. By analyzing more than one dimension of care, rather than focusing on a single one, this study gains a broader perspective on informal care and is thus more comprehensive/robust than others.

This said, in this dissertation, I propose to answer the following research questions: 1) Who are the informal caregivers? 2) What are the impacts of caregiving on their personal and professional life? 3) How do informal caregivers perceive the impact of the Informal Caregiver Statute on their lives? and 4) Is the Informal Caregiver Statute sufficient to address their problems or what additional policies and/or social aid should be adopted in Portugal to support informal caregivers? To achieve this, I conducted semi-directive individual interviews with two different stakeholders: informal caregivers, and an actor of the civil society (a member of the National Association of Informal Caregivers). The interviews were conducted in different regions of Portugal (n=15): five were conducted in northern Portugal; four in southern Portugal; and six in the archipelago of Madeira<sup>1</sup>. While geographic diversity was not a requirement to successfully accomplish this research, I found that informal caregivers' struggles, or lack thereof, vary locally. This comparative research between the country's regions is yet to be found in informal care literature, which deems this research clearly relevant, as it addresses another important literature gap. Regarding the caregivers, I have chosen to only include in my qualitative sample those who care for a dependent elderly person, since the majority of policies aimed at supporting carers are usually designed for working parents, neglecting the existence of caregivers that provide care to elders (José & Wall, 2004; Soeiro et al., 2020; Naldini et al., 2016). Hence, the analysis of the struggles of these caregivers will hopefully be fruitful in two ways: 1) to give them more visibility, and 2) to allow for the creation and development of policies that consider their real needs. Finally, it is important to note that although my analysis is gendered, since care in all its facets

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<sup>1</sup> More specifically, five on the island of Porto Santo, and one on the island of Madeira.

is deeply feminized, I will also consider the realities of men who do care work. Nevertheless, women will remain the focus of my research.

With this said, this dissertation is organized as follows: a) a literature review on social reproduction theories, the care sector, work-care reconciliation, and social care regimes; b) methodology; 3) a discussion of the findings; and 4) some concluding remarks.



## CHAPTER 2

# An Analysis of Social Reproduction Theories

### 2.1. Women in the “Unproductive” Sphere of Work

*“It is a tragic paradox that the bases of love, dependence, and altruism in human life and the historical oppression of women have been found within the same matrix” (Zaretsky, 1982, p.193).*

In the late 60s and 70s, with the emergence of second-wave feminism, the origins of women’s oppression were a hot topic of discussion among activists and theorists (Winders & Smith, 2019). While it was clear to them that the line separating private and public life shifted over time due to cultural changes, they were not sure why women always remained relegated to the private sphere (Tronto, 1993). What causes might explain this subjugation? Modernization theorists saw biological differences between the sexes as a possible answer (Brenner & Laslett, 1989). De Beauvoir (1949) argued that men are biologically privileged, making them more productive and valuable to society. On the contrary, women must endure the pains of reproduction and the subsequent servitude of motherhood, elements that reduce their availability for work outside the home and thus ensure their confinement to the sphere of unproductive and invisible care work<sup>2</sup>.

While biological factors are certainly a point to consider, as they contribute to the unequal sexual division of labor, for Marxist feminists this answer is superficial and can be reduced to biological determinism. For them, women’s oppression is produced and reproduced by society’s capitalist mode of production and the structure of class relations (Giménez, 2018; Arruzza, 2016). The unequal relationship between the capitalist mode of production and reproduction is the explanation for the secondary status of women in society since the productive sphere will always triumph over the reproductive one, shaping it according to its need to generate labor (Arruzza, 2016). Ferguson (1999) explains this idea in a very clear way: in a world where everything is commodified, including labor, the abandonment of the household in order to earn a wage makes individuals dependent on the market for their subsistence. This creates a cycle of dependency in which the reproductive sphere of life becomes less important and in which there is a

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<sup>2</sup> De Beauvoir’s (1949) explanation of women’s oppression was not only based on biological specificities. She raised two more reasons: 1) the role occupied by women in the capitalist mode of production; and 2) the desire of men to reduce “*the other*” to a place of submission.

“subordination of unwaged labor to waged labor” (Giménez, 2018, p.23), and thus of women to men, depending on their socioeconomic class.

However, this theorization remained uncontested only until the 80s, when postmodern/poststructuralist approaches and identity politics gained relevance (Giménez, 2018). These early social reproduction theorists criticized the fact that the reproduction of labor power was not sufficiently assessed in the Marxist framework (Rodríguez-Rocha, 2021), that the importance of race and gender was not theorized (sex-bling categories) (Federici, 2021), and that these analyses were economically reductionist (Giménez, 2018; Ferguson, 1999) and based on the assumption that productive and paid labor were synonymous (Mezzadri, 2019). The Marxian theory of value, which sees value-generating processes as inherent only in the productive sphere of life (Mezzadri, 2019), was now under attack. New schools of thought were emerging. Academics such as Mariarosa Dalla Costa (1975), Selma James (1975), Silvia Federici (2012), and Maria Mies (1986) argued that reproductive activities such as housework, childbearing, and care work are fundamental to capitalist production, not only producing use value but also essential to the production of surplus value. Without them, economic systems would be unlikely to thrive because the basic human needs of society would be permanently unmet (Waring, 1999). Despite this, the exclusion of reproductive unpaid work from economic analysis is still very latent. This is the result of valuation biases that prioritize markets over communities, culture over nature, and rationality over emotion (Bjørnholt McKay, 2013).

While these works were fundamental in formulating the early stages of Social Reproduction Theory (SRT), they were mostly criticized for their dualism – conceptualizing capitalism and patriarchy as two separate spheres (Ferguson, 1999) – and lack of depth<sup>3</sup>. In fact, they only analyzed the Fordist way of life – that of a white middle-class working family, where the man is the breadwinner (producer, earning a family wage) and the woman is a dependent housekeeper and/or mother (reproducer) (Winders & Smith, 2019).

## **2.2. New Realities – Neoliberalism and the Blurring of Private and Public Life**

These shortcomings have been addressed in modern SRT. First, by presenting a unified front regarding women's oppression - stemming from their dual engagement in productive and reproductive activities (the renewal of workers) (Vogel, 1983); and second, by giving voice to the realities of women living in the Global South. In this sense, the contemporary concept of social reproduction has been expanded to encompass other spatial realities, being sensitive to the role that race, gender, and colonial dynamics play

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<sup>3</sup> Feminist Marxists also criticized these approaches by stating that class was carelessly theorized, being reduced and equated to concepts such as gender and race (Giménez, 2018; Rodríguez-Rocha, 2021).



in class exploitation<sup>4</sup>. It is also important to recognize that the openness of the concept was partly set in motion by the rise of neoliberal thought in the mid-1970s and the urge to combat it (Winders & Smith, 2019). Phenomena such as deindustrialization, de-unionization (followed by a decline in real wages), and various welfare reforms created an urgency to dismantle the ideals of a past Fordist society (Winders & Smith, 2019), as women found themselves entering the labor market out of necessity. This change not only transformed women's lives, but it also affected the organization of families, shaping gender roles and class dynamics (Musumeci & Solera, 2013; Tronto, 1993).

In this way, the distinction between productive and unproductive work, which capitalism had introduced, and which normalized the idea of two separate gendered spheres of life, public and private, began to blur. While it is still true that women are disproportionately represented in the private sphere of domestic life, their entry into the labor force recognized them not only as caregivers but also as workers, producers of goods. In addition, the commercialization and commodification of social reproduction activities also contributed to the erasure of this line (Winders & Smith, 2019). This profound social transformation led feminist geographers to pay more attention to the hierarchies and relations formed within and between the unwaged and the waged, as well as the interdependence of productive and reproductive work, and its importance in the production of urban realities (Winders & Smith, 2019). Since there is no longer a distinction between work and home, private and public, the household is no longer analyzed in isolation, but accompanied by other variables – civil society and the welfare State –, as they shape its reality. Indeed, when the State is unable or refuses to be a provider; and when civil society cannot make up for this lack, social reproduction becomes privatized, individualized, and mostly centered on women (Winders & Smith, 2019).

This individualization and lack of State response, typical of neoliberal policies and austerity measures, blurs the line between life and work since it is now the responsibility of a family member to take care of all social reproduction activities (Rodríguez-Rocha, 2021). In this sense, there is no space for leisure, as life is reduced to a constant cycle of work (Rodríguez-Rocha, 2021; Winders & Smith, 2019). Thus, while women are economically free, they remain chained to reproductive tasks, juggling paid and unpaid work and the emotional labor that both entail. This double workload has been mentioned by several scholars (Chatzidakis et al., 2020; Toupin, 2018), with Benston (1969) arguing that only when social reproductive activities stop being enshrined in the private sphere will women truly be as free as their counterparts. However, under the rule of neoliberalist ideas, which value competitive markets and robot-like workers, it becomes difficult to make a statement for the transposition of care into the public sphere, since the norm is to visualize it as the

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<sup>4</sup> Social reproduction encompasses the reproduction of the human species, the reproduction of the labor force, and the reproduction and continuation of care relations within private and public institutions (Mezzadri, 2019; Winders & Smith, 2019; Giménez, 2018; Brenner and Laslett, 1989).

responsibility of the citizens, who lose their value when recurring to the help of welfare policies (Chatzidakis et al., 2020). As a result, welfare States are dismantled through the privatization of human struggle. This shift of responsibilities from the State to individuals raises one serious question for the future: who will assume the responsibility of care once families are no longer capable of supporting dependent family members? (Bjørnholt & McKay, 2013). This will be discussed in the following chapters.

## CHAPTER 3

# The Care Sector

### 3.1. Care: Definition and Dimensions

In the existing literature, there is an ongoing debate about how to define care. For scholars such as Fisher and Tronto (1990), care can be seen as everything we do to maintain, repair, and sustain our well-being in the world. This is the most comprehensive definition of care, encompassing not only human interdependence but also all the relations that humans can form with objects and the environment (Tronto, 1993). Within this framework, care is seen as a collective, ongoing process: a relationship between more than one person that has a beginning and an end and whose distribution can be shaped politically, culturally, and historically (Fisher & Tronto, 1990). Scholars with narrower views tend to contest this conceptualization and limit the exercise of care to specific contexts and groups. While specificity may be good when studying a particular group of people, and thus a narrower definition may be useful, this dissertation will not benefit from this approach because one could make the mistake of excluding carers from the analysis by circumscribing the definition of care. In contrast, a definition that views care as a continuum, with different components that may come into conflict with each other, is better suited to policy formulation because it considers all periods of a lifecycle and will help us understand what care entails in the lives of informal caregivers.

The process of caregiving is divided into four interrelated stages (Fisher & Tronto, 1990). The first, *caring about*, refers to the stage in which there is a recognition that care is needed, and should be provided. The second, *taking care of*, begins when the caregiver takes responsibility for addressing this need and how to respond to it. The third, *caregiving*, is the materialization of the first two stages. Finally, the fourth stage is *care-receiving*, which involves the object of care accepting and responding well to the care received. Because the caregiving process involves the needs and desires of two or more people, it is natural for conflicts to arise within and between these stages. For example, it is common for the caregiver to decide what is necessary to meet the care recipient's needs. This tends to take away the autonomy and independence of the care recipient, who feels ignored (Tronto, 1993). On the other hand, caregivers may also feel that their needs are not being met because they have little time for themselves.

This said, care, and its dimensions, can be theorized in three different ways: 1) care as an emotion; 2) care as a demand; and 3) care as a social relationship (Rummery & Fine, 2012). When care is viewed as an emotion, it is defined as concern for the well-being of others: the "other" being a dependent child, a sick parent, a spouse, a friend, a neighbor, or even a stranger. While this is an extremely important facet of care,

some scholars tend to reduce it to a feeling of affection, love, reciprocity, and connection (Toupin, 2018), failing to recognize that caregiving might not be fulfilling and meaningful to all. This conceptualization deeply romanticizes caregiving, constructing it as a labor of love. The second dimension of care, as a demand, seems to fill this gap, where care is seen as a form of work/burden that is time-consuming, physically demanding, and potentially damaging to the caregiver's physical and mental health. Finally, care can be seen as a social relationship: while intimate, familial, and safe, it can also be complex, reinforcing power dynamics, dependency, and conflict (Rummery & Fine, 2012). Regardless of the definition chosen, it is important to note that care, whether voluntary or involuntary, always implies a notion of intergenerational and familial obligation (Gil, 2020).

### **3.2. The Faces of Informality**

An informal caregiver is someone who provides unpaid care outside of a professional context (Eurocarers, 2021a). This definition encompasses all types of caregivers, irrespective of their age, the intensity of care provided, and their degree of closeness/kinship with the recipient of care. Although any family member can become an informal caregiver, the pressure to take on this role continues to fall overwhelmingly on the arms of women, for historical, political, material, and cultural reasons (Gil, 2021; Soeiro et al., 2020; Ehrlich et al., 2020; Rummery & Fine, 2012). The tendency is not to try to mitigate gender inequalities in reproductive work by dividing tasks between the sexes, but to constantly pressure women to take on these responsibilities (Soeiro et al., 2020). In fact, when a child or an adult develops care needs, the first source of help is almost always a middle-aged woman in her late forties or fifties (Naldini et al., 2016), who may be a spouse and/or mother, living in the same household (Ehrlich et al., 2020). This gendered caregiving trend continues when it comes to children caring for a dependent parent. Daughters are more likely than sons to become caregivers because they tend to feel more obligated to their parents' needs and feel more remorse if they fail to provide quality care (Ehrlich et al., 2020). Nevertheless, there are various cases in which men take on the role of caregiver. In these situations, however, their role is associated more with household and care management tasks than with the provision of care itself, which does not mean that the task is any less intensive or important (WHO, 2022; Eurocarers, 2021a; Keck & Saraceno, 2010). What it does suggest, however, is that even care can be gendered, with women taking responsibility for physical and emotional caregiving.

Physical caregiving can take two forms: assistance with instrumental activities of daily living (iADLs), such as cooking or cleaning; or assistance with activities of daily living (ADLs), such as feeding, bathing, dressing, toileting, and assisting with mobility (Ehrlich et al., 2020; Zigante, 2018). These activities include constant supervision of the care recipient when the person cannot be left alone for long periods due to safety risks. In this way, the need to be available and accessible throughout the day depends on the range of activities provided by the caregiver: iADLs tasks can be performed at any time of the day, while ADLs are

time-sensitive and leave little room for delay (Ehrlich et al., 2020). Depending on this and the level of responsibility undertaken, informal caregivers may assume the role of primary caregiver – when they provide more than half of the care needed by the dependent person – or secondary caregiver – when they provide less intensive tasks that usually allow them to remain employed (Ribeiro, 2007). Nevertheless, informal caregivers usually do not like this division. For them, it is difficult to see what distinguishes a primary caregiver from a secondary caregiver, since the struggle to care for someone is common to both types of carers. It is not the number of hours or the type of caregiving activity that indicates the intensity of care or the nomenclature of the caregiver, but the feeling of burnout and pressure that they experience (Le Bihan & Martin, 2012). Therefore, the primary caregiver may be the one who manages and organizes the care setting and not necessarily the one who is involved in the daily life of the care recipient (Le Bihan & Martin, 2012).

Furthermore, we must never forget that the caregiver also provides emotional and psychological support to the care recipient. Eldercare, unlike childcare, which is usually predictable in terms of both time and intensity (Ehrlich et al., 2020; Eurocarers, 2017a), emerges unexpectedly and hence is characterized by higher levels of physical and emotional burnout on the part of the caregiver<sup>5</sup>, who usually cannot count on the help of respite services due to their unavailability (Eurocarers, 2017a). To add to this, and due to the long hours spent providing care, informal caregivers tend to also feel isolated, frustrated, stressed, and helpless (Zigante, 2018). As a matter of fact, it is hard to find caregivers who were not forced into the position by external forces. In the literature we can find the following reasons as to why they did so: 1) a sense of reciprocity or moral obligation towards the dependent person (Ribeiro, 2007); 2) a question of necessity (Ribeiro, 2007; Ehrlich et al., 2020); 3) to avoid feelings of guilt (Ribeiro, 2007); 4) to avoid institutionalization and/or its financial costs (Ribeiro, 2007); 5) to feel altruist (Ribeiro, 2007); 6) due to proximity (emotional and physical) and availability reasons (Amaral et al., 2020); 7) due to spirituality, faith, and religion (Ribeiro, 2007); 8) to obtain social and family recognition (Ribeiro, 2007); 9) due to a distrust in the quality of services provided by institutions due to overcrowding or lack of professionals (Soeiro et al., 2020); and 10) to obtain material rewards (Ribeiro, 2007).

While many of these reasons are emotional, others, such as the skepticism of formal institutions and the economic barriers associated with them, are the result of failed approaches to care. In the next subsection, I will look at the care sector and analyze how the EU has dealt with it.

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<sup>5</sup> According to Eurocarers (2017a), informal carers are 20% more likely to have mental health problems than non-carers. This figure increases when informal carers provide intensive care, i.e. more than 20 hours per week. Physical health is also affected.

### 3.3. The Professionalization of Care

When analyzing the trends in European countries' care policies, it is unusual to find one that does not opt for a combination of different types of strategies, be they public, private, or both, to address caregiving. This combination of solutions, or as various scholars have described it, this "welfare mix" (Le Bihan & Martin, 2012), may lean more towards a public or private approach, depending on the country's institutions and government's ideological position. In this way, it is not possible to find a pattern between models of organization, financing, allocation of benefits, or conditions of access between countries' care systems (Peña-Longobardo & Oliva-Moreno, 2022; Eurocarers, 2017a). What can be found, however, is that all Member States rely, to a greater or lesser extent, on non-professional family care as a complement to formal publicly provided care services, depending on how the care responsibility is divided between the State and the family (Jacobs, 2003). Despite these differences, LTC systems face a common challenge: an increasingly elderly population. By 2070, 13% of the European population will be over 80 years old (Peña-Longobardo & Oliva-Moreno, 2022). This progressive aging is expected to lead to an increase in public spending on LTC, as more people will require care services for longer periods (Wieczorek et al., 2022; European Commission, 2019; Bjørnholt & McKay, 2013)<sup>6</sup>. Therefore, policymakers must not only design policies that can ensure comprehensive, high-quality care in the EU but also uphold the financial viability of the entire care system (Wieczorek et al., 2022).

This reality has already been acknowledged by the EU, which understands that with an aging population, the sustainability of the LTC and public pension systems will be put to the test (European Parliament, 2022a; Courtin et al., 2014). In fact, this is already happening. If we look at the formal care infrastructures present in the EU, they can cater only to a third of the elderly population in need of support (European Parliament, 2022a). While this societal pressure for more LTC services is currently being alleviated by the unpaid work of informal caregivers, this reliance will not be possible for much longer, since we are now facing a care crisis (Federici, 2012), i.e. a shortage of professional and non-professional carers to meet the needs of care recipients. This crisis resulted from the combination of different events: a) global economic changes; b) the entry, and increasing participation, of women in the labor market (which altered gender roles and the way families are structured: intergenerational cohabitation and family networks have declined) (European Parliament, 2022a; Courtin et al., 2014; Musucemi & Solera, 2013; Da Roit & Naldini, 2010; Tronto, 1993); c) a rise in old-age dependency, due to an ongoing demographic crisis; d) a constant appearance of regulations raising the retirement age across Europe (Da Roit & Naldini, 2010); and e) a greater dependence of children in urban contexts (Soeiro et al., 2020; Le Bihan & Martin, 2012).

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<sup>6</sup> According to the European Commission (Wieczorek et al., 2022), public spending on LTC will rise to 2.7% of Gross Domestic Product by 2060. In 2013 the average was 1.6%.

To fight this caregiver gap, and to ensure that the care sector does not collapse, by 2030 the EU will need to have 11 million newly trained health professionals to meet the demand for LTC (Eurocarers, 2021b). If not, in 2060 it is likely that the supply of informal care will be insufficient to respond to Europe's demand (Courtin et al., 2014). For this reason, the EU considers undeniable that a substitution from non-professional to professional care will have to take place, as well as a prioritization and upscaling of community-based care, since the majority of LTC services are outdated (European Parliament, 2022b). To ensure this, the current EU policy trajectory has focused on conceptualizing carers as co-workers (Twigg, 1989), by formalizing and recognizing their care provision. By doing so, formal and informal carers would work in cooperation, with the family/community becoming semi-professionalized and part of the formal system. To ensure that this idealization is achieved, there are several measures that directly or indirectly target informal caregivers, such as 1) the payment of allowances; 2) contracting; 3) the provision of training and counseling; 4) the recognition and validation of the skills gained while providing care (Zigante, 2018); and 5) the possibility of informal caregivers to pay national insurance contributions to build their pensions while caring (Zigante, 2018). These policies aim to offer caregivers a choice, as well as financial independence and flexibility (Le Bihan & Martin, 2012). As a result, two new types of caregivers would emerge: a) semi-formal family carers, who are subsidized by the State for their work, appearing as complementary actors to the formal care sector; and b) informal carers, who, while not employed by a formal institution, are paid for their caregiving activities (José, 2012).

However, the enforcement, design, and regulation of these policies vary across countries and may lead to different outcomes. Cash-for-care policies, which can be paid directly to the caregiver – with or without an employment contract –, or indirectly – the cared-for person receives the allowance and then chooses to remunerate their caregiver<sup>7</sup> –, are an example of this. While in some countries this financial support is “up for grabs”, with the State imposing few restrictions on who is entitled to benefit from them, in other cases the cash transfers are highly regulated and tightly controlled: income, level of disability, relationship with the user, and the intensity of care are some of the variables to have in consideration (Zigante, 2018). Regardless of whether a person meets all of these requirements, the value of these allowances is usually too low to externalize care to formal care services or even to replace the income lost due to caregiving activities.<sup>8</sup> Regarding other professionalization paths, variations are present across countries (in terms of quality and availability). Training for carers exists in almost all EU countries and is mainly provided by civil society (Zigante, 2018). However, this provision is very fragmented as it is directly linked to government spending

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<sup>7</sup> Indirect allowances are the most commonly used approach in Europe. However, it is extremely difficult to assess whether the money given to the dependent person has reached the hands of the caregiver or not (Zigante, 2018). This issue can be counterbalanced with more regulatory measures.

<sup>8</sup> This reality is only challenged in Sweden, where informal caregivers are formally employed (by their municipality or care recipient) and receive a fixed, taxable salary, similar to those given to formal care workers (Zigante, 2018).

on LTC. Furthermore, this training, when available, is usually not accompanied by a validation/certification of the caregiving skills, which may prevent informal caregivers from pursuing a formal caregiving career (Zigante, 2018).

In addition to these measures, an increasing number of EU Member States have adopted policies that reinforce “aging in place”, in order to reduce the number of institutionalizations (Wieczorek et al., 2022, p.145). While the shift from institutional to home-based care is usually supported by care recipients, who prefer to receive care in their homes (Wieczorek et al., 2022; Zigante, 2018), this approach has come to be favored as an alternative to other, more expensive institutional LTC options (Wieczorek et al., 2022; Zigante, 2018). As a matter of fact, the encouragement of home-based services can be seen as a way to contain costs, since the investment in institutional care involves more State expenditure<sup>9</sup>. Even though this approach brings economic benefits to governments, and is favorable to care recipients, not all the players involved in the game emerge victorious. Carers will continue to suffer from the psychological and emotional stress of providing care (as long as support policies are not in place).

### **3.3.1. The Weight of the Care Sector**

Today, the formal care sector accounts for about 12% of total global employment, or 381 million workers, the majority of whom, two out of three, are women (Soeiro et al., 2020). This figure increases exponentially when the informal unpaid care sector is considered, bringing the number of workers to 2 billion, or more than 76 million people<sup>10</sup>. Of these workers, 61.4% are women (providing 2/3 of all informal care [Eurocarers, 2022]) with less education, who combine paid work and care, providing an estimated 18.25 hours of care per week (Peña-Longobardo & Oliva-Moreno, 2022). The economic value of these unaccounted hours, up to 72.000 million per year, if formally carried out, would represent about 3,64% of Europe’s GDP and an annual salary of 7.567€ per worker. (Peña-Longobardo & Oliva-Moreno, 2022). In Portugal, the number of people providing some form of unpaid care is estimated to be between 800.000 and 1 million workers (Soeiro et al., 2020), with the European Commission pointing to 13% of the population (Soeiro et al., 2020). However, since it is difficult to estimate the number of people who provide some form of unpaid care due to the invisibility of these workers, different conceptions of what constitutes care, the difficulty of registering as an informal caregiver in some countries, and cultural expectations (Courtin et al., 2014), it is safe to say that this number is even higher in reality.

In its Care Strategy (European Commission, 2022), the EU recognizes the importance and contribution of informal carers to care systems and the need to support these individuals, who provide over 80% of all

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<sup>9</sup> For instance, Finland managed to save 2.8 billion euros per year on formal care due to the country’s investment in informal care provision (Wieczorek et al., 2022).

<sup>10</sup> More than 50 million people are registered as informal caregivers in Europe (Eurocarers, 2022).



care in Europe (Zigante, 2018; Eurocarers, 2022). The Care Strategy also calls on Member States to develop national action plans to improve the availability, accessibility, and quality of care services, which could be supported by EU funding<sup>11</sup>. The EU has also been advocating for work-life reconciliation policies, capable of improving working conditions, without neglecting other caregivers' needs. Examples are: 1) offering counseling, training, psychological and financial support to carers; 2) increasing the offer of quality care services and guaranteeing that the infrastructures are accessible to people with disabilities; 3) ensuring that LTC care is affordable; 4); investing in the development of digital technologies to support care provision; 5) promoting collective bargaining and social dialogue in order to improve wages and working conditions; and 6) the creation of awareness campaigns to tackle the gender stereotypes of care (European Commission, 2022; European Parliament, 2022b).

While this programmatic document, like many others, demonstrates the commitment of policymakers to the issue of care, they are not legally binding, remaining as suggestions to the Member States, and therefore having little to no implication in the daily life of carers<sup>12</sup>. While some might argue that care commitments should be enshrined in the EU legislation and enforced by national courts, the deep cultural and institutional diversity of EU Member States hinders the adoption of common transnational policies. Countries should then implement a policy mix that can respond to the care needs of their population, always keeping in mind the guidelines provided by the EU (Eurocarers, 2021b).

Unfortunately, even though the European Union has called, “in a sense”, for more funding for LTC (European Parliament, 2022b), this has been a challenge (Zigante, 2018). In fact, it would be dishonest to forget that although the EU has been claiming for more public investment, their approach has been mainly to favor cost-containment policies. Thus, the majority of EU countries pursue these types of measures, by externalizing the responsibility and costs of care to those engaged in reproductive activities – in this context, informal caregivers are seen as a subsidy to capital (Mezzadri, 2019; Le Bihan & Martin, 2012).

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<sup>11</sup> ESF+, InvestEU, EU4Health Programme, the Recovery and Resilience Facility, and the European Structural and Investment Funds are only some examples of funding provided by the EU (European Parliament, 2022b).

<sup>12</sup> Only the Work-life Balance Directive is binding (European Commission, 2019). It instituted the carers' leave, providing a minimum of 5 working days per year to caregivers, and access to flexible working arrangements.



## CHAPTER 4

# Work and Care Conciliation Theory

### 4.1. The Impact of Caregiving on Employment Patterns

The reconciliation of paid work and family life has always been an issue in contemporary Western societies, as it affects patterns of productivity, reproduction, and gender equality (Naldini et al., 2016). It is not surprising, therefore, that research on work-life reconciliation has led to the implementation of public policies that address caregiving in the workplace. Unfortunately, these policies have not been designed in a universalistic manner, with working parents of infants being the only caregivers encompassed<sup>13</sup>. While the importance of eldercare has been theorized (having many societal implications), it is mainly discussed in terms of the impact of an aging population on the tax burdens of younger workers (Kotsadam, 2011; Casado-Marín et al., 2011). The neglect of these caregivers in the arena of labor legislation puts them in a situation where they are forced to prioritize work over family, or vice versa. As a result, caregivers may face greater or lesser opportunity costs, that increase throughout their lives and have adverse long-term consequences even long after caring (WHO, 2022; European Parliament, 2022a; Ehrlich et al., 2020; Van Houtven et al., 2013). In the most extreme cases, where the effect of caregiving on employment is extensive, caregivers are forced to leave the labor market or retire earlier in their lives than they would have without caregiving. In contrast, when the impact is intensive, caregivers tend only to reduce their work hours, take on fewer responsibilities, or forgo promotions to accommodate caregiving responsibilities (Carmichael & Charles, 2003).

Although there is a significant number of caregivers who have to completely withdraw from the labor market, various studies show that the impact of caregiving on employment is usually intensive (Da Roit & Naldini, 2010; Wolf & Sold, 1994), with carers being able to remain employed by reducing working hours (Spiess & Schneider, 2003; Naldini et al., 2016; Ehrlich et al., 2020). To these scholars, the decision to leave the labor market completely is normally due to the role of other variables, such as the intensity and type of care being provided (Van Houtven et al., 2013; Casado-Marín et al., 2011; Carmichael & Charles, 2003; Heitmueller, 2007; Crespo, 2006; Spiess & Schneider, 2003; Naldini et al., 2016); and the living situation of the caregiver (Casado-Marín et al., 2011; Heitmueller et al., 2010; Heitmueller, 2007; Naldini et al., 2016). Hence, they conclude that caregivers who help with ADLs are more likely to withdraw from the

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<sup>13</sup> This trend has gradually been erased, with more countries implementing legislation that takes into account eldercare and its impacts on (women's) employment.

labor force than those who only help with iADLs, since in the first case care involves a greater time commitment on the part of the caregiver, who, due to the time-sensitivity of the care activities performed is unable to postpone them (Van Houtven et al., 2013; Casado-Marín et al., 2011; Heitmueller, 2007; Crespo, 2006; Carmichael & Charles, 2003; Spiess & Schneider, 2003; Naldini et al., 2016). This same reasoning is applied to the intensity of care: depending on the number of hours spent providing family care, employment hours are proportionately reduced (Van Houtven et al., 2013; Casado-Marín et al., 2011; Heitmueller, 2007; Ehrlich et al., 2020). In the same way, coresidential living situations also affect negatively working arrangements, as in these cases the greater geographical proximity between caregiver and care recipient foments the provision of more intensive care (Carr et al., 2018; Casado-Marín et al., 2011; Heitmueller et al., 2010; Heitmueller, 2007; Naldini et al., 2016). Thus, employment is more affected, with bigger opportunity costs to the carer (Van Houtven et al., 2013).

Nevertheless, the literature on the impact of caregiving on employment is not heterogeneous. Ehrlich (2018) argues that living settings and types of care are not significant in labor market participation when family care intensity is controlled. Caregivers providing extra or co-residential care have the same likelihood of harming their employment situation. The same can be said for caregivers providing ADLs or iADLs. For the scholar, the number of hours providing care is what explains negative labor market outcomes. Similarly, there is no consensus on the variables that might exacerbate opportunity costs. While to some, costs are influenced by the caregiver's level of education and income - the higher the income, the more reluctant individuals are to give up work, and the easier it is to externalize care, due to higher incomes (Crespo, 2007; Keck & Saraceno, 2010; Da Roit & Naldini, 2010) –; others deny that employment status is significant (Spiess & Schneider, 2003). This is in line with the findings of Kröger and Yeandle (2014) and Carr et al. (2018), who argue that financial well-being alone (or lack of it) does not explain labor market exit. For them, caregivers are more likely to quit or reduce their employment participation if their relationship with the care recipient involves feelings of love, concern, obligation, intimacy, reciprocity, and responsibility. Furthermore, individuals with fewer economic resources might be able to keep on working due to the support of family networks and geographical proximity (Da Roit & Naldini, 2010; Keck & Saraceno, 2010).

Gender also negatively affects caregivers' employment trajectories (Kotsadam, 2011; Keck & Saraceno, 2010). While it is true that men face greater opportunity costs by earning higher wages, women are typically the ones who incur these costs by assuming the role of the primary caregiver within the family (Keck & Saraceno, 2010). This happens primarily because it makes more sense for women to quit work and specialize in unpaid care work, due to lower wages, but also because their decisions are deeply connected to "intra- and intergenerational family care responsibilities" (Ehrlich et al., 2020, p. 1394). This is particularly the case in countries where formal institutional solutions are not available to common citizens, forcing women to take on the social responsibility of care. This lack of choice affects women's employment patterns more

negatively than men's (Carmichael & Charles, 2003), forcing them to seek flexible working arrangements in order to balance care and work. Occupational segregation and downgrading are usually their only solution.

However, not all caregivers choose to reduce their attachment to the labor force, but rather to reduce their leisure time. Whichever option is chosen – leaving or staying in the labor force –, the impact on caregivers' quality of life is felt cumulatively over the years, resulting in reduced old-age pension entitlements, career stagnation, economic dependency, physical and mental health problems, isolation, and less time for themselves (European Parliament, 2022a; Eurocarers, 2016; Naldini et al., 2016). Eurofound's European Quality of Life Survey (Eurocarers, 2017b) states that 42% of non-employed carers are in the lowest income quartile, compared to 24% of non-carers. Furthermore, the care penalty for women is estimated to reach €242 billion per year (European Parliament, 2022a). Therefore, carers are more likely to be at risk of poverty in old age, having difficulty making ends meet.



## CHAPTER 5

# Social Care Regimes

### 5.1. Typologies

Over the years, and especially since the 90s, many countries in the EU have adopted major LTC reforms (Fisher et al., 2021; Zigante, 2018). These policy reforms, which differ from country to country due to the degree and extent of State intervention in the field, and the involvement of civil society, family, and culture (Naldini et al., 2016), have implications at the micro and macro levels (Fisher et al., 2021). At the micro level, the way care services are structured affects the quality of life of both care recipients and care providers, as their emotional, physical, and economic lives can be improved or worsened by them. At the macro level, the organization of the labor force and gender relations are intertwined with the presence of adequate care arrangements (Fisher et al., 2021).

Following the work of Sarraceno (2010) and inspired by Esping-Andersen's (1990) typology of welfare regimes, Naldini et al. (2016) classifies social care regimes in terms of the division of care responsibilities between different institutions: the market, non-profit organizations, but most importantly between the State and the family. How the division and subsequent distribution of responsibilities takes place promotes different degrees of defamiliarization or familialism in a country. Three patterns can be found: 1) Familialism by default, or unsupported familialism, when the responsibility of providing care rests on the shoulders of the family since publicly provided alternatives and financial provisions are non-existent; 2) Supported familialism, when the State supports families with parental leaves, payments for care, or tax relief; and 3) Defamiliarization, when there is a high range of accessible and of quality public services, that can be publicly or privately financed (Naldini et al., 2016).

The defamiliarization/familiarization spectrum typology was also adopted by Leitner (2003), who categorized countries as having optional familialist care regimes or implicit familialist care regimes. Countries in the implicit familialist cluster externalize the responsibility of care to the family, while countries in the optional familialist cluster "burden" the State with this responsibility. Regardless of which of these two very similar typologies we choose, empirical evidence has shown that in countries that defamiliarize care by investing in State-supported LTC services that are available to all, individuals are not pressured to take on the responsibility of caregiving. This has a positive impact on women's choice to remain employed, as they no longer are obliged to provide care, and the possibility of externalizing it emerges as an option (Eurocarers, 2021a; Van den Broek & Grundy, 2020; Eurocarers, 2017b; Kotsadam, 2011).

Moreover, when the choice to care is voluntary, informal carers are supported by the existence of paid leaves, pension rights, and cash benefits. The opposite happens when familiarization is high.

Employment patterns are influenced by the degree of policy defamiliarization (Van den Broek & Grundy, 2020; Naldini et al., 2016). When the State invests in affordable and high-quality care services, employment is encouraged, and informal care is reduced. On the other hand, when the State prefers to support informal carers through unregulated “cash for care” policies (financial transfers and allowances to beneficiaries), families tend to continue to take on the responsibility of care, and thus employment is frowned upon, and informal care flourishes. This happens since the allowances given to informal caregivers appear as a substitute for work, and thus create “incentive traps”, influencing individuals to cut their links to the labor market (depending on the value of the financial transfer and its strictness) (Naldini et al., 2016; Zigante, 2018). Thus, in countries where financial provisions are not restricted to buying out-of-home care, re-familialization tends to appear (Naldini et al., 2016)<sup>14</sup>. Hence, although at first sight this approach appears good, it fails to improve gender equality within families (Musumeci & Solera, 2013).

## 5.2. The Portuguese Care System

According to Esping-Andersen’s (1990) typology, Southern European welfare States, such as Portugal, can be classified as corporatist, due to, but not limited to, their strong ties to the Church and the almost total absence of State intervention in the private sphere. For these reasons, the social responsibilities that should be taken care of by the State, such as the care of the elderly and children, are delegated to the family and to the Church – usually Catholic nonprofit organizations (Adão e Silva, 2002), – which appear as substitutes for the lacking and underdeveloped infrastructures of care (Lopes, 2017). The principle of subsidiarity is very present in these countries, with the State intervening in the care arena only when the family’s capacity to help is completely exhausted. In this way, Portugal is one of the examples of a country with implicit familism, due to its low offer of formal public care services, and its rudimentary social protections (José, 2012). Moreover, the strong link with the Church helps to ensure that traditional family and gender norms are maintained, ensuring that women’s place remains outside the public sphere of life (Esping-Andersen, 1990).

The Portuguese care regime combines public and private responses (usually controlled by State-subsidized nonprofits) (Lopes, 2017). Regarding public solutions, informal caregivers can benefit from compensatory subsidies and direct monetary transfers from the State. Examples of these benefits are the

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<sup>14</sup> In countries where cash benefits are generous, unregulated, and paid to the dependent, the informal market is fueled. This happens because care recipients prefer to be cared for at home rather than in institutions. Thus, the money received is usually used to pay for care within the family – through the creation of a “family caregiver” –, or to externalize care to other informal carers, usually migrant workers (this trend is observed in Italy). On the other hand, when cash benefits are regulated, the formal care market is encouraged (Zigante, 2018).



dependent person's supplement and the allowance for assistance to a third person (Soeiro et al., 2020). Although these compensatory measures can be seen as a first step to aiding caregivers, they are insufficient in returning the freedom of these individuals, since the monetary help doesn't cover the externalization of care to formal services. In fact, the low values of these direct transfers are shocking if we take into consideration the increased cost of living, as well as the loss of purchasing power of the population. Regarding the dependent person's supplement, the amount received is stipulated not only by the degree of dependency of the beneficiary, but also by their contributive career, or lack of it. Thus, the State can pay the beneficiaries a value between 115,94€ (given to someone with a first-degree dependency and no contributive regime) and 208,69€ (given to someone with a second-degree dependency and a contributive regime). Meanwhile, the third-person care allowance is a monthly benefit of 117,73€, given to families with descendants, to compensate them for taking care of a dependent person permanently. Thus, they receive a family allowance with a disability bonus (Soeiro et al., 2020).

Additionally, informal caregivers can also rely on the help of catholic foundations, such as *Santa Casa da Misericórdia*, and *Private Social Solidarity Institutions (IPSS)*<sup>15</sup>. These institutions offer a range of care services, such as daycare centers for children and the elderly, residential structures for the elderly, home support services for the elderly and occupational activity centers, and residential homes for people with disabilities. However, these solutions correspond to a semi-privatization (Lopes, 2017) of the care system, and even though they are co-financed by the Portuguese State<sup>16</sup>, they remain out of reach to the common working citizen, who usually cannot afford them. While this care network has more than 11 thousand social facilities and serves more or less 400 thousand people (Soeiro et al., 2020), it is obvious that its (semi) private nature reduces the potentialities and reach of the whole network.

### **5.3. The Informal Caregiver Status: An Ongoing Fight for Recognition in Portugal**

Even though informal caregivers have been fighting since 2016 for the acknowledgment of their work as such, the legal recognition of informal care work in Portugal was only set in motion with the passage of the regulatory decree n°100/2019 (DRE, 2019a), in 2019, which created and approved the Informal Caregiver Status. However, prior to this date, other initiatives had already been put in motion by informal caregivers in order to give more visibility to their fight and the challenges faced by them daily. In 2016 they submitted

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<sup>15</sup> They can also rely, to a lesser extent, on *Mutualidades*.

<sup>16</sup> For each user institutionalized in a residential structure for the elderly, IPSS receive from the State 395,57€ per month. If the elder in question has a second-degree dependency, they are offered a bonus of 109,39€, plus 51,58€ per month if their institution is offering services to a population of 75% of elders with this degree of dependency. Additionally, for each beneficiary receiving domiciliary care, IPSS receive 269,63€ per month (Soeiro et al., 2020).

a petition with 8.057 signatures to the National Assembly, demanding, among other measures, the reinforcement of the National Network of Continued Care (to help ensure carers' rest); the promotion of mutual help groups; the reduction of working hours by 50% for those combining work with care, without salary loss; tax deductions for those caring for someone with a degenerative illness; the availability of a third party that could provide domiciliary support to the dependent person in case of the absence of the informal caregiver; the promotion of information, training, and counseling for informal caregivers and dependents; and more estatal support (AR, 2016).

From these demands, informal caregivers were only able to pressure the government to adopt the ICS, a document that resulted from the discussion of several draft bills presented by the political parties with electoral representation at the time (Araújo & Soeiro, 2021). As a result, the document embodies a mix of diverse care perspectives, reflecting the distinct ideological stances of the parties involved: with the right-wing conceptualizing care as love – an altruistic, selfless act that should remain in the domain of families; and the left wing conceptualizing it as labor – a demanding involuntary task, whose social responsibility should fall to the State. According to Araújo and Soeiro (2021), three models of approaching care can be drawn from the analysis of the ICS: 1) a familialist approach; 2) a socialization approach; and 3) a hybrid approach, where care can be set in informal non-market relationships, but the fomentation of informal unregulated work is frowned upon.

In the first case, the centrality of the family in the care process is not questioned, with conservative values continuing to be upheld in society. The State's role is that of assistance to families, through allowances. However, their often-conditional nature means that only very impoverished families have access to them (Araújo & Soeiro, 2021). Hence, the most vulnerable groups in society – children and the elderly – have to rely on informal networks of care sustained by intergenerational solidarity, as the State provides only the bare minimum, ensuring the burden of unpaid reproductive work falls on women. This approach was advocated by the Social Democratic Party (PDS, center-right) and the Social Democratic Center-People's Party (CDS-PP, right) when discussing the ICS.

The PSD views informal care as an alternative to institutionalization, defining it as a “voluntary and selfless commitment to the well-being of family members, friends and neighbors” (PSD, 2016, p.1). In 2019 the party defined an informal caregiver as an individual who “accompanies and provides regular third-party care, voluntarily and without remuneration, to a person in a situation of dependency” (PSD, 2019, p.7). The implication of the term “voluntary” is unmistakable: it conveys an ethos of care driven by affection, portraying caregiving as an endeavor of love and consequently, a voluntary and uncomplicated decision. In the same draft law, they also state that “the work of the informal caregivers is beneficial not only for the person being cared for but also for society in general” (PSD, 2019, p.17). In the same way, the CDS-PP views informal caregiving as a service to the community (Araújo & Soeiro, 2021). For them, State should

focus on providing social support to carers through subsidies and hiring processes, so that caregivers formally assume the role of partners with health services. In their bill no. 1126/XIII/4.<sup>a</sup>, they say “informal caregivers, family and friends, are the primarily responsible for the health of dependent people, constituting true partners of health services and providing a share of care that can amount to 80% of what the patient needs” (CDS-PP, 2019, p.2). Thus, the role of family as partners should continuously be fomented, holding caregivers responsible for this service.

The Socialist Party (PS, center-left) can also be included in this category. In its Draft Resolution no. 306/XIII/1.<sup>a</sup>, the party places significant emphasis on the role of informal community care networks, reinforcing their existence. The PS suggests that the government should promote “an innovative policy to support families, neighborhood networks, and other social support networks, and motivate them to care for people in their homes”, as well as “give special emphasis to the role of the family in society, improving the conditions and well-being of informal caregivers (...)” (PS, 2016, p.4). This underscores a familialist perspective on care, where the fomentation of informally is justified by the State’s support for families (in the case of PS, by advocating for carer’s rest; the capacitation of caregivers; and the availability of psychological help).

The second approach that inspired the ICS is the complete opposite. Instead of keeping care work where it traditionally has been, in the domesticity of the family, efforts are made to transpose it to the public realm, rebranding it as a collective responsibility (Araújo & Soeiro, 2021). In this case, redistribution and social justice are at the center of the debate, with issues such as inequality and precarity being raised. The hardships faced by informal caregivers are also emphasized. As Araújo and Soeiro (2021) put it, this approach does not try to challenge the notion that reproductive work is unproductive, instead, it aims at stopping the informality of the sector. As a result, the priority of the State should be to strengthen public services and formalize care, thus recognizing and sharing the burden of caregivers. This position was particularly defended by the Portuguese Communist Party (PCP, left) and the General Confederation of the Portuguese Workers - National Intersindical (CGTP-IN), which argued for more investment in public formal services, as well as social protection for carers. For them, the creation of a Statute would not ensure the protection of caregivers, but the commodification of care, turning them into partners in LTC systems (Araújo & Soeiro, 2021). In its place, they recommended the reinforcement of support measures – through the increase in the values of the allowance for third-party assistance and the dependency supplement – and the creation of a quality public support network for families (PCP, 2018).

Finally, the third approach, mainly defended by the left-wing bloc (BE, left), and People-Animals-Nature (PAN, left), is a combination of the above. While it criticizes the involuntary, often compulsory nature of informal care, that forces women to leave their lives behind, it does not seek to erase decommodified community networks of care (Araújo & Soeiro, 2021). The responsibility of care in societies

should not be primarily on informal caregivers, but the recognition of their work is essential. Ergo, the State's responsibility should pass not only through the strengthening of public formal care services but by the design of measures encouraging informal family care, such as leaves tailored to male individuals, in order to mitigate gender inequality and the division of labor (Araújo & Soeiro, 2021). Care leaves, flexible working hour arrangements, vacations, and counting caregiving time for retirement purposes are also incentivized, to facilitate a healthy balance between paid work and care. In this way, it is ensured that care is a choice. Furthermore, and contrary to the second model, in this case, informal work is not seen as unproductive, with advocates recognizing its value without its need to be formalized in the labor market (Araújo & Soeiro, 2021).

Several measures were brought forward by the BE to ensure this: a) the guarantee that Informal Caregivers can benefit from a leave of 30 days to assist a dependent; b) working hour reduction to provide care; c) the possibility of opting for part-time work; d) flexible working hours; and e) the right of carers to rest for at least 4 days each month, by organizing efforts with the National Network of Integrated Continued Care (NNICC) (BE, 2018). Similarly, PAN also suggested the granting of employment rights, allowing the caregiver to reconcile the act of caring with the exercise of a professional activity (PAN, 2019). These measures resemble the ones proposed by the BE, only adding the right to telework and the attribution of fiscal deductions. The PS also positioned itself in the middle ground regarding informal care. While institutional responses were sought in their proposal, familialist views were not left behind. This is seen in their recommendation for the creation of an Informal Caregiver Allowance (as seen in Draft Law no. 186/XIII/4.<sup>a</sup>, PS, 2019). While thoughtful, the constraints imposed made it clear that this support was only to be given to family members, excluding carers with no kinship to the care recipient to be supported. Here, familialist notions bar non-family carers' recognition.

Although these political stances are not rigidly enshrined in the ideal-model types proposed by Araújo and Soeiro (2021), their analysis helps us navigate the party's dialogues and organic.

### **5.3.1. Overview: The Rights enshrined in the ICS**

The ICS is the legal document that regulates the rights and duties of Portuguese informal caregivers and care recipients, establishing support measures for them (DRE, 2019a). It was initially implemented in only 30 pilot project municipalities, but since June 2020 it covers the entire national territory (with the Autonomous Regions of Madeira and Azores having autonomy in its enforcement and contents). For caregivers to apply for recognition, they must be caring for someone who is entitled to a third-person care allowance or a second-degree dependency supplement (DRE, 2019a). Its recognition comprises two types of caregivers: primary and secondary.

Legally, a primary caregiver “is considered to be the spouse or *de facto* partner, relative or relative up to the 4<sup>th</sup> degree of the straight line or collateral line of the person being cared for, who accompanies and cares for that person on a permanent basis, who lives with them in a shared household and who does not receive any remuneration for their professional activity or for the care they provide to the person being cared for.” (DRE, 2019a, p.9). Primary caregivers, due to a 100% cut in their incomes (derived from leaving the LM to care), are entitled to a monetary support measure: the Informal Caregiver Support allowance, which has a reference amount of 480,43 € (the value of the Social Support Index)<sup>17</sup>. This subsidy is allocated according to the household’s means (DRE, 2019a). Additionally, they can also access the Voluntary Insurance Scheme (*Seguro Social Voluntário*). Regarding re-entering the LM, their integration is promoted (DRE, 2019a).

A secondary informal caregiver “is considered to be the spouse or *de facto* partner, relative or relative up to the 4<sup>th</sup> degree of the straight line or collateral line of the person being cared for, who accompanies and cares for that person on a regular, but not permanent basis, and may or may not receive remuneration for their professional activity or for the care they provide to the person being cared for” (DRE, 2019a, p.9). Regarding their employment situation, they are entitled to all measures tailored to promoting the reconciliation of paid work and caregiving (DRE, 2019a).

Regardless of their designation, caregivers are entitled to a list of rights brought by the ICS: a) to see their work as carers recognized by society; b) to receive training, in order to offer better care to the cared-for person; c) to receive information from health and social security personnel; d) to benefit from psychosocial/psychological support from health services, even after the dependent’s death; e) to benefit from a student-worker caregiver statute when attending an educational institution; f) to be attributed a health professional of reference; g) to participate in caregivers’ self-help groups; h) to be heard in the design of public policies; i) to be referred to social support networks, specifically home-based support; and, j) to benefit from rest days<sup>18</sup> (DRE, 2019a).

The ICS’s content overview reveals its familialist influences, endorsed by the PDS, CDS-PP, and PS. The exclusion of non-family caregivers from acknowledgment/recognition illustrates the government’s perspective on care, deeming it primarily a family responsibility. The stipulations on social support (as in the case of the informal caregiver allowance) are also rooted in familialistic stances. Therefore, informal caregivers are viewed as partners of the State (Araújo & Soeiro, 2021). The approach on the Informal

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<sup>17</sup> Only primary caregivers without a fixed income are eligible for receiving this support. Caregivers receiving unemployment benefits, or on unpaid leave, are not entitled to it (DRE, 2019a).

<sup>18</sup> These rest days could be achieved by the referral of the cared-for person to three infrastructures: 1) the National Network for Integrated Continue Care (NNICC); 2) to residential structures for the elderly or residential homes; and c) to home-based services, when the provision of domiciliary care benefits the person being cared for (DRE, 2019a). In the cases where the dependent would be referred to the NNICC, the amount paid would have a positive differentiation (DRE, 2019a).

Caregiver Statute of the Autonomous Region of Madeira mirrors this perspective, albeit with some variations. While the importance of the family is strongly underscored, statutory recognition is not exclusive, as the regional government acknowledges that individuals without family connections can also provide care to their loved ones. Moreover, there is no differentiation among caregivers: all are eligible to receive financial assistance. Although there are conditions for receiving this support, they are distinct, taking into consideration the economic situation of both the informal caregiver and person being cared for, the level of dependency of the care recipient, whether the individuals are receiving other forms of support, the intensity of care provided by the informal caregiver, and the number of people being cared for by them (DRE, 2019b).

Despite these differences, the organic of both Statutes is the same. Therefore, it becomes relevant to analyze, after four years of its implementation, its results. Do they correspond to what all caregivers had advocated? Are they effective in improving their lives? Are they lacking in content? This will further be analyzed.

## CHAPTER 6

# Methodology

To gather and analyze information about the perception of specific actors regarding care work in Portugal, individual semi-directive interviews were employed, as well as the analysis of Draft Laws and Resolutions presented by the political parties with parliamentary seats. I interviewed fifteen informal caregivers (through the snowball sampling method), and a member of the National Association of Informal Caregivers (*Associação Nacional de Cuidadores Informais*). Different backgrounds, geographies<sup>19</sup>, trajectories of care, and characteristics of the informal caregivers were considered. I interviewed four types of informal caregivers: 1) caregivers who voluntarily left the labor market to provide care; 2) caregivers who were forced to leave the labor market to provide care; 3) caregivers who were unemployed/retired before providing care; and 4) caregivers who conciliate/conciliated caregiving and paid work.

In this dissertation, informal caregiving in Portugal is analyzed at its micro and macro levels through a qualitative approach. At the micro level, informal caregivers' quality of life (health, financial situation, and social life), caregiving pathways, and feelings regarding care are analyzed. At the macro level, I focused on the labor organization paths of informal caregivers, as well as the gender dynamics associated with caregiving. Both at the micro and macro level, the dimensions under scope depend on, and are deeply intertwined with the existence, accessibility, degree of development, and structure of public care services and estatal support. Therefore, the perceptions of informal caregivers regarding the functioning of these services are also considered, being supplemented by legislation analysis. Therefore, the following dimensions of care were analyzed in my semi-directive interviews: a) caregiving; b) relationship with the labor market; c) estatal support/aid; and d) community ties.

In terms of legislative analysis, I examined national parliamentary activity from 2020 to 2023 to gauge any possible changes in the party's approach to the care sector after the introduction of ICS in 2019. The Draft Laws and Resolutions under scope focus only on measures regarding the elderly, as these are usually put aside by governments. Hence, I conducted a critical content analysis of the interest legislation found in this period.

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<sup>19</sup> As mentioned in the introduction, the interviews were not all conducted in the same region of Portugal. Five were conducted in northern Portugal; four in southern Portugal; and six in the Madeira Archipelago (five on the island of Porto Santo, and one on the island of Madeira).

## 6.1. Ethical Considerations

Concerning ethical issues, this dissertation did not raise any, as all interviews conducted were anonymized to protect the integrity of each person involved in this study. The interviews were recorded with the written informed consent of the interviewees, for transcription purposes only, and were immediately erased afterwards. Additionally, I have obtained written approval from the ethics committee at my university to conduct this research. Having said that, in the next subsection, I present the empirical results of the study, analyzed with the help of the program MAXQDA. The feminization of informal unpaid care work was not forgotten in this analysis, with all data being looked at through a gendered lens. Information on the characterization of CGs (caregivers) is presented in Table 1.<sup>20</sup>

*Table 1 - Sample Characteristics*

| Sample Characteristics |     |     |              |               |                                 |                     |                           |              |
|------------------------|-----|-----|--------------|---------------|---------------------------------|---------------------|---------------------------|--------------|
| Number                 | Age | Sex | Civil Status | Kinship       | Educational Background          | Labor market status | Caregiving hours per week | Cohabitation |
| CG1                    | 59  | F   | Single       | Niece         | Secondary education (9th grade) | Unemployed          | ≥40h                      | X            |
| CG2                    | 59  | F   | Widow        | Wife          | Secondary education             | Self-employed       | 20-40h                    | X            |
| CG3                    | 46  | M   | Single       | Son           | Master's Degree                 | Self-employed       | ≥40h                      | X            |
| CG4                    | 36  | F   | Single       | Daughter      | Secondary education (9th grade) | Employed            | 20-40h                    |              |
| CG5                    | 41  | F   | Single       | Daughter      | Bachelor's Degree               | Unemployed          | ≥40h                      | X            |
| CG6                    | 32  | F   | Single       | Granddaughter | Secondary education             | Self-employed       | ≥40h                      |              |
| CG7                    | 67  | F   | Divorced     | Daughter      | Secondary education             | Retired             | ≥40h                      | X            |
| CG8                    | 55  | M   | Married      | Son           | Secondary education             | Employed            | 20-40h                    |              |
| CG9                    | 51  | F   | Married      | Daughter      | Secondary education             | Employed            | 20-40h                    |              |
| CG10                   | 43  | F   | Single       | Daughter      | Secondary education (9th grade) | Employed            | 20-40h                    | X            |
| CG11                   | 62  | F   | Married      | Daughter      | Secondary education             | Employed            | 20-40h                    |              |
| CG12                   | 59  | F   | Married      | Wife          | Bachelor's Degree               | Employed            | ≥40h                      | X            |
| CG13                   | 46  | F   | Single       | Friend        | Post-graduate degree            | Employed            | ≥40h                      |              |
| CG14                   | 66  | F   | Widow        | Daughter      | Primary education (6th grade)   | Retired             | ≥40h                      |              |
| CG15                   | 49  | F   | Single       | Daughter      | Bachelor's Degree               | Employed            | ≥40h                      | X            |

<sup>20</sup> These characteristics existed at the time of the interviews. In the cases where respondents were no longer caring at the time of the interview, this information refers to their last caregiving experience.



CHAPTER 7  
**Empirical Findings**

**7.1. The Care and the Caregivers**

*Table 2 - The care experience*

| Number | Motivation             | Tasks performed  | LM care related changes                         | The care experience             |  |                  |  |               |
|--------|------------------------|--|---|---------------------------------|--|------------------|--|---------------|
|        |                        |  |   | Previous care experience        | Formal support   | Informal support | Financial help   | ICS-Knowledge |
| CG1    | Love                   | Cooking; Cleaning the house; Care management                                 | Career interruption                             | Provided care to both parents   | Daycare center; Physiotherapy; Diaper Allowance              | X                | Third-person care allowance                                | -             |
| CG2    | Availability/Proximity | Bathing; Cooking; Help with locomotion; Companionship; Care management       | Reduction in working hours                      | -                               | -  | X                | -  | -             |
| CG3    | Availability           | Cooking; Dressing; Companionship   | -   | -                               | Daycare center; Nursing home                                 | X                | -  | X             |
| CG4    | Proximity              | Cooking; Bathing; Doing the laundry; Care management;                        | Career interruption; Reduction in working hours | -                               | -  | -                | Dependent person's supplement; Third-person care allowance | X             |
| CG5    | Proximity              | Companionship; Care management   | Career interruption                             | -                               | -  | X                | -  | -             |
| CG6    | Availability           | Feeding; Assisting with bathroom use   | -   | -                               | Health center nurses   | X                | -  | -             |
| CG7    | Availability           | Cooking; Cleaning the house; Care management; Companionship                  | Reduction in working hours; Early retirement    | Provided care to her sister     | -  | -                | -  | X             |
| CG8    | Availability           | Cooking; Bathing; Care management; Helping the dependent lie down and get up | -   | -                               | Nursing home   | X                | -  | X             |
| CG9    | Love                   | Cooking; Dressing; Washing clothes; Bathing; Companionship                   | -   | -                               | Nursing home   | X                | -  | -             |
| CG10   | Proximity              | Cleaning the house   | -   | Provided care to her father     | -  | X                | -  | -             |
| CG11   | Proximity              | Care management; Helping the dependent get up; Bathing                       | -   | Provided care to her father     | Nursing home; Social security home-based assistance          | X                | Dependent person's supplement                              | X             |
| CG12   | Availability/Proximity | Care management; Driving; Help with locomotion                               | -   | -                               | -  | -                | -  | X             |
| CG13   | Love                   | Care management  | -   | -                               | -  | -                | -  | -             |
| CG14   | Proximity              | Cooking; Care management; Bathing; Companionship; Cleaning the house         | -   | -                               | Daycare center   | X                | -  | -             |
| CG15   | Proximity              | Cooking; Bathing; Helping the dependent lie down and get up; Care management | -   | Provided care to another person | Home-based assistance; Nursing home; Long-term care facility | -                | Dependent person's supplement                              | X             |

Fifteen informal caregivers (all Portuguese) with very different caregiving stories make up the sample used in this dissertation. As noted above, the majority of these caregivers care for or have cared for a dependent elderly person. As such, this analysis will naturally shed more light on the daily lives and problems they, rather than other caregivers, experience. Nevertheless, this sample is far from homogeneous, although certain patterns and specificities are common to all respondents. The first and most striking, but expected, result of the analysis of this sample is the discrepancy in the number of male and female caregivers. Out of 15 caregivers, only 2 were male. Despite this, there are differences between the sexes to be seen in this sample, something that will be discussed later. Regarding the age of the respondents, most of them fall within the middle-aged category, between 45 and 59 years old. I also conducted interviews with 4 caregivers below this quartile and 3 caregivers above it, resulting in a range of ages from 32 to 67 years old. The educational background of caregivers is another factor that impacts their journeys and challenges. While there is significant diversity in their responses, most caregivers have completed only high school, with some having attained only 6 or 9 years of education. However, it is noteworthy to mention that this sample also includes caregivers with higher educational achievements: 3 hold bachelor's degrees, 1 has a master's degree, and another possess a post-graduate degree (see Table 1).

Moreover, concerning their marital status, out of the total number of informal caregivers, 8 are single, 4 are married, 2 are widowed, and 1 is divorced. These figures show that informal caregivers tend to be unmarried, or lack other non-normative forms of romantic relationships, which translates into the absence of a partner's support (although this does not imply that they lack informal support networks of help, as we will see further on). Regarding the caregivers' familial relationship with the care recipient, it can be observed that 8 were daughters, 2 were sons, 2 were wives, 1 was a granddaughter, 1 was a niece, and 1 was a friend. This large number of daughter/son caregivers may be related to the already advanced age of the dependent person, who often has already lost their partner, or, in other cases, who is also debilitated, being unable to provide any type of care. Hence, this responsibility falls on the shoulders of the next closest relatives, the children. Several caregivers cite the death of their parent's partner, or their old age, as the reason they had to step up. Others refer the non-existence, non-availability, or unwillingness of other family members to assume the caregiving role:

*In my sister's case, because my parents were old, and her children were young. In my mother's case, because only I am available [to care for her]. (CG 7)*

And also:

*Because look, he [her father] didn't have a wife anymore. My brothers...I have brothers, but they didn't want to...hmm...they didn't care much about him. (...) And so I had to take over that job myself because nobody else wanted to. My brothers did not care, and I was already the closest to him. (CG 4)*

This last statement introduces yet another topic for analysis: the consistent and often enduring absence of male family members assuming responsibility or aiding with caregiving tasks. Although this sense of unavailability can be expressed by any family member, regardless of their gender, women tend to experience a stronger sense of duty, obligation, and remorse in caring for an ill parent. A caregiver that had to institutionalize her mother in a nursing home, after 2 years of taking care of her, refers feeling guilty for “failing” her:

*[Caregiving] is the duty of family members. I still think what I did is little, I always carry a guilty conscience because my mother is in a nursing home. I couldn't do what she did for her mother. But I really couldn't take it anymore. (CG11)*

This moral compass that seems to only affect women is deeply connected with conservative and normative gender ideals that defend the role of women as nurturers and carers. Intergenerational obligation and reciprocity are also variables in this game. This clearly marks the way caregivers think:

*I take care because I am at home. And even if I wasn't at home, it is normal. As long as I can, it will always be like that. (CG10)*

Moreover, there is an unquestioned assumption that women are the ones expected to undertake the caregiving role within families, while men are free to continue to pursue their professional and social lives. These patriarchal notions were found in various interviews, with women stating them unconsciously and in a conformed and resigned way. When asked what motivated her to take care of her mom, a caregiver answered the following:

*For love, because it is my mother. And because maybe I am also the only daughter in the family. (CG9)*

Another caregiver, who has 5 sisters and 3 brothers, talked happily about the division of caregiving tasks between the daughters of the family, and of all the help she received from them. When asked if she received this type of help from her brothers, or if the responsibility of care fell only on the arms of women, she explained that 2 of her brothers lived very far away from their mother, and that the other one, even though living in the same household as the recipient of care and being single, did not help. She stated:

*No, [the responsibility] falls only on us women. It's all on us, we are the ones who manage his life for him, too. (CG14)*

It is noteworthy that these women not only bear the responsibility of caring for their sick mother but also have to assume the role of personal unpaid domestic workers for their brother, who does not contribute, in any way, to the functioning of the household. This overlapping of reproductive activities (domestic and care) was not found in any other interview.

Besides assuming caregiving tasks for reasons of love, and obligation, the majority of informal caregivers stated that availability and proximity were the reasons that made them assume the role, followed by the high prices practiced by the formal semi-privatized care sector. Despite the different motivations and the diverse illnesses of the care recipients, the informal caregivers of this sample, in general, provide the same type and intensity of care to their dependents (see Table 2). Out of the 15, 9 offer holistic care, comprising ADLs such as feeding, bathing, dressing, assisting with bathroom use, helping the dependent get up and lie down, and helping them walk; iADLs like cooking, cleaning the house, and doing the laundry; socio-emotional support in the form of companionship; and care management activities, such as accompanying the dependent to doctor appointments, treatments, and administering medications. The remaining 6 help with one or more of these categories<sup>21</sup>. Regarding the intensity of care, 9 caregivers provide more than 40 hours of care per week, while the rest provide between 20 to 40 hours. Interestingly, the number of hours spent caring is not associated with cohabitation patterns, as 3 of the caregivers providing more intensive care ( $\geq 40$ h) do not live with their care recipients (see Table 1).

Also common to all caregivers, regardless of their living arrangements, is the daily struggles they must endure. Physical and psychological wear and tear are very present, with caregivers stating that they often feel/felt tired due to caregiving activities. Those providing ADLs reported experiencing physical fatigue, particularly in the form of back pains, with one caregiver even referring having aggravated her calcification problem due to the demands of caring for her father alone. While physical wear and tear were only mentioned by a handful of carers, psychological deterioration was a common experience to all, often leaving them with permanent damage long after care had ceased.

*Yes, I felt a bit [psychological distress]. I felt it and I didn't heal. I was a very calm person before taking care of my parents. Because of caregiving I became very anxious, and I still am today. It was something that stayed. It is a malady. There was even a time when my brother told me that I must have hidden depression, because I was feeling so low. On a psychological level it affected me a lot. (CG11)*

For the caregivers who still have a dependent person in their care, a constant feeling of tiredness, fear, and frustration is displayed. Most of them argued that only through a great deal of inner strength and hard work can they remain sane. The limited time caregivers have to rest also ends up exacerbating these feelings. When asked if they had time to unwind, the majority (11) answered with a simple no. The remaining said that in specific situations, with a great deal of family logistics, they were able to, but never completely. The fear that something bad could be happening outside of their presence, putting their loved ones at risk, always lingered in the back of their minds. This fear, coupled with a great deal of skepticism regarding the capability

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<sup>21</sup> It is important to note that many of the women interviewed who were caring for a family member did not mention helping with household chores, as for them this was an everyday task unrelated to the caregiving responsibilities.

of other family members to provide care, leads to caregivers becoming socially isolated from other environments. Nevertheless, this was not always the case: for some caregivers, it was the dependents themselves who did not allow them to leave their side, demanding attention; for others, it was the lack of formal and informal solutions that prevented them from having a full social life; yet for others, and even with the help of networks of informal support, they did not feel understood by their peers, or refused to share their daily struggles with them, leading them to create their “own social segregation”:

*I had no one to talk to. The only person I talked to was a friend of mine. I didn't even talk to my daughter, we did not want to worry her about the disease, she didn't know. (CG12)*

*I feel alone and helpless. There aren't that many people. People of my age, 36, nobody is in my situation, so there is a situation where you don't get involved in the group. It's not that I only talk about this, I don't, but they are really people who have a different maturity than me, and I can't keep up with them in bars, clubs, things like that. (CG4)*

The power dynamics inherent in caregiving, stemming from the care recipient's reduced autonomy and independence, are also felt in the daily lives of both caregivers and those they care for, potentially giving rise to conflicts. The wishes of dependents are often not in line with their needs, which can provoke in them and in caregivers feelings of frustration. However, conflicts do not always happen between caretaker and care receiver. An informal caregiver taking care of her friend recounts the frequent clashes she would often have with her friend's family:

*The difficulty for me was managing my help. That is, to what extent I was not getting ahead of the relatives. But on the other hand, I also felt that if I helped too much, they might also be a little put off. It was difficult to manage that. Even though they often thanked me for the care, I felt that the family was watching everything that I did to see if they caught me slipping. I often had conflicts with them because they didn't agree with my way of helping her, even though they hadn't informed themselves in any way about my friend's condition. What was best for her. So it was really very difficult (CG13).*

This reality can easily be overlooked, given that caregivers are typically family members rather than individuals without any familial connection to the care recipient. They must not be forgotten.

Also important to remember and analyze is the relationship informal caregivers form with the LM, whether it is a relationship of absence or permanence. Among the 15 caregivers interviewed, 10 were able to remain employed throughout the caregiving period (3 were self-employed); 3 were unable to do so, with 2 being left on unpaid leaves; and 2 had already retired, with 1 forced into early retirement due to caregiving responsibilities. It is important to note that out of the 3 caregivers who were unemployed or on unpaid leave, 2 were able to successfully re-enter the labor force, having had only a “short” interruption of their careers. However, their caregiving trajectories diverge significantly: a) one is no longer caregiving due to her

mother's passing, allowing her to resume full-time work at her previous job; b) another secured a new job but continues to care for her father, having to usually reduce working hours for caregiving; and finally, c) the remaining caregiver, on unpaid leave, continues to provide full-time care for her aunt, thus hindering her return to the workplace. Concerning the employed caregivers, 2 also referred to had had to reduce their working hours to care, and several others stated having difficulty in conciliating paid work and caregiving.

## **7.2. The Political Perspective: Perceptions of Better Support to Informal Caregivers**

### **7.2.1. The Perceptions of Informal Caregivers**

Besides the issues related to the caregiving process itself, caregivers also expressed encountering complications derived from lack of statal support. This institutional distance affected them on several fronts. The first and most immediate problem they faced when assuming the role of carer was the dearth of available information to which they were submitted, both by health organizations and social security agencies. Caregivers stated not being informed, let alone capacitated, on the proper ways to care for their ill loved ones. This obviously impacts their awareness and hence degree of care provided, reducing its quality to a great extent. Furthermore, this disinformation has ripple effects, directly affecting their physical and mental well-being. This lack of support from health professionals in offering them the information and equipment needed to care at home was described by most caregivers (9), who referred feeling alone in the task of care, often not knowing who to turn to when they were unable to meet the needs of the care recipient. For them, measures such as providing them with training, counseling, a health professional of reference, and more tailored support would be fundamental to battle this issue. Moreover, some caregivers also argued that a further capacitation of health professionals should be made since they felt that they do not have the skills to care, nor to inform others how to do so in a domiciliary context.

This misinformation is also latent in the legal field, with many caregivers unaware of their rights. Only 4 out of 15 caregivers benefit/benefited from any type of monetary allowance, with only 1 receiving both the third-person care allowance and the dependent person's supplement. Although a possible reason explaining this small number of users is the unfamiliarity regarding these subsidies, others are presented by the caretakers, such as 1) the excessive bureaucracy involving the whole process of application; 2) the delay in the allocation of the money; 3) the low value of the subsidies, that aligned with the difficulty in getting them, deem them no longer desirable; 4) the dissemination of false information by social security personnel; and 5) forgetting to resort to subsidies since the care provided is being done out of love, and thus support is not looked after. For caregivers with a certain financial stability, it is too much work to apply for an

allowance that will not even be sufficient to cover the expenses related to caregiving, as well as for the externalization of care to a formal service.

Regarding the utilization of formal care services, there is an uptick in numbers, as 8 caregivers indicate their current or past engagement with them (see Table 2). However, resorting to formal services was only thought of when they no longer had the means to provide care at home, and the costs were assumed entirely by them. In fact, only in 3 cases, some sort of public help was given to the caregivers, by health centers – through the provision of monthly allowances to help the caregivers buy diapers for their dependents; by ensuring a home service where nurses would help the caretakers do the hygiene of the patient; and by paying medication bills – and social security – through the provision of home-based support and physiotherapy. Despite this help, respondents reported having to do some financial gymnastics to make ends meet. Furthermore, even when financial difficulties are/were not a concern for the caregivers, it is noted by all that the prices promoted by the Portuguese care sector are exorbitant (particularly when considering the services provided), making it extremely hard to institutionalize someone without external help. State co-funding is not usually an option, since only a small percentage of individuals can exit the waiting lists in place. On top of this, caregivers also complained of the insufficient caregiving infrastructures existing in the country, which do not correspond to the real needs of the population, and some referred having a lack of confidence in these services and their professionals:

*Daycare is very expensive. And it depends on the daycare center, doesn't it? Because you see on the news those centers that hurt the old people and I get scared. I get sick from what I see on the news. They leave the old people to starve, to freeze, or they don't change their diapers... but then a good daycare center is more expensive, and I can't afford it with only her pension. (CG6)*

*They don't have enough professionals to look after people properly. (...) Besides, the people who work there have no training in the area. (CG7)*

Whether taking advantage of formal services or not, it is interesting to note that most caregivers (10) have informal community support networks (see Table 2). To some extent, these tend to replace, and complement, formal networks when they fail to respond or are unavailable. Some interviewees shared that they would usually talk with close relatives, friends, and even clients to clarify doubts and get help. This reliance on community connections can be seen below:

*I called my sister-in-law and said, "Look, Auntie's probe came out. I don't know how it's going to be. It's Saturday, we don't have a nurse at the medical center." And she said, "Hang on, I'll find a friend". (CG1)*

Nonetheless, this informal assistance should not, and cannot, fully substitute formal support networks of help. To address this issue, as well as others previously mentioned, caregivers proposed several solutions,

such as the enhancement of the knowledge of social security staff regarding carers' rights, enabling them to offer more accurate information; the development of the existing care infrastructure; the de-commodification of care; and an increase in the recruitment of formal care workers. Additionally, caregivers feel entitled to complimentary physiotherapy sessions, cost-free home-based assistance, emotional support, and time to rest from caregiving duties. Although these measures are already enshrined in the Informal Caregiver Statute, nearly all the participants in the sample are unaware of their existence (8) (see Table 2). Moreover, even those who claim to be aware of it are not conscious of its contents, and thus the implications it could have in their lives. As a matter of fact, only 2 caregivers seemed to be truly acquainted with the document, with one of them being a beneficiary. When asked if she felt any changes after getting the Statute, she answered the following:

*No, no. It's just a piece of paper I have. (...) It's a piece of paper that I get from the social security office every 3 months or 6 months. I go anywhere and the Statute does nothing for me. (CG4)*

Besides this non-paradigm shift, the carer is also displeased about the nomenclature division made in the document. In her eyes, it is not because she is labeled a secondary caregiver, instead of a primary, that she is less deserving of certain rights. The exclusion of secondary caregivers from possibly receiving monetary support – the informal caregiver subsidy – is a point that she clearly makes throughout the whole interview regarding the unfairness of the Statute. For her, the division does not make sense, since there is not a primary caregiver in the family, and the intensity of her care is equal to that of a primary caregiver, or even more so since she cares and works. Cohabitation being a pre-requisite to receive the allowance is also frowned upon by her. This nomenclature discontentment is also shown by the only other caregiver informed about the Statute, who vehemently stated that she refuses to benefit from it because she does not want to be called a secondary caregiver. Plus, she referred that not taking advantage of the Statute has no deep consequences, since she knows the rights are not being enforced. This non-enforcement is the source of a lot of frustration, with the caregivers knowing that they are being robbed of the possibility of having an easier life, especially when regarding their career and educational progression. For them, the Statute and other forms of government aid are visibly not a remedy to the issue of conciliation of professional and personal life. Thus, based on their perceptions, they believe that what could produce direct positive results against this would be the enforcement of remote working (when possible), the existence of paid leaves, home-based assistance, and Statal reimbursement of salaries. Through these measures, caregivers believe they would gain time to develop themselves and rest.



### **7.3.2. The Perceptions of the National Association of Informal Caregivers**

The Statute has also been a letdown for the National Association of Informal Caregivers (NAIC), beginning with its delayed implementation. Although the law was approved in 2019, it was not enforced until June 2020, and even then, only in 30 pilot project municipalities. This immediately created a geographical barrier that prevented many caregivers from benefiting from the Statute during this period. Those that did, about 1.000 people, as per the NAIC, saw as help only the payment of a support allowance. The remainder of the caregivers' promised rights were not realized due to the pandemic situation, and remain unexecuted until now, with ordinances yet to be created. Hence, so far, and according to the NAIC, the impact of the ICS has been minimal, and the knowledge of it even smaller. For them, this is due to a remarkable lack of information, which is frequently exacerbated by social security personnel who tend to convey inaccurate information or leave out crucial details when interacting with caregivers, primarily because they often lack a comprehensive understanding of the Statute. The lack of requests for recognition from caregivers is also due to the process being extremely bureaucratic and largely carried out through digital platforms (especially during COVID-19), with digital literacy not being a strong skill for many carers.

Regarding the informal caregiver subsidy, which has emerged as the only direct outcome of the application of the Statute, it has its problems, being marked by excessive constraints, referred to by the Association as: 1) the differentiation between primary and secondary caregivers, with the allowance exclusively accessible to primary caregivers due to their usual lack of employment and stable source of income to cover caregiving costs; 2) a means test that considers household income, thereby excluding certain caregivers from eligibility; and 3) its inadequately low monetary value. A member of the Association sheds light on the topic:

*The support allowance that reaches half a dozen people has a series of conditions that will in no way support the informal caregiver. The way the caregiver support allowance was conceived is wrong. Because we don't have to rely on the economic resources of the family, or the fathers, or the mothers, or the husbands, or anyone else. And the allowance is designed to be based on the household income as a whole, which excludes a number of families. So us carers are still doing a job, replacing the State, and we don't have any kind of economic condition of our own. We are still dependent on our families. So there are many [caregivers] who don't get paid because of their household, and those who do are so poor that the expenses always end up being to cover the fixed expenses or expenses of the person being cared for. So we need to rethink the allocation of the allowance. (NAIC)*

For NAIC, the lack of economic power, most often associated with involuntary and precarious withdrawals from the labor market due to care tasks, is one of the major problems faced by caregivers. Hence, the ICS needs to be revised in order to mitigate this and all its other inconsistencies. However, not

everything about it has been a failure. The visibility and importance given to the group, as well as the recognition of its work, increased following the 2019 implementation:

*Since we started talking about legislation, and since politicians got involved, there has at least been a call for society in general to pay attention to informal care in the country. It had always existed, but no one had ever remembered that they [caregivers] needed to have rights in order to be able to provide care. This was an obligation for families, and as it was an obligation nobody asked for anything. So I think yes, that there has been a wake-up call. (NAIC)*

However:

*We're still a long way off, a long way off, from there being a great awareness in civil society of informal care. I notice that in people of my generation. And I hope that your generation no longer thinks like mine and my mother's. This [caregiving] is not an obligation, it has to be an option. (NAIC)*

Regarding government support, the Association feels like there is a lack of political will, foreseeing no imminent improvements in the lives of caregivers in the near future:

*It's one thing to draw public attention to the existence of informal caregivers. Another thing is the political will to implement measures to support informal caregivers. And for me, there still is not much political will, and I've never understood why, because the budgets have been made and never spent. (NAIC)*

Hence, and as a direct critique of the existing legislation, the Association is now fighting for a full amendment of the Statute, having launched a citizens' legislative initiative (CLI) defending: the extension of the recognition of carer to those who not being relatives, provide care, having emotional ties to the dependent; the extension of the recognition to underaged individuals who provide care to their parents; the removal of the condition that the cared-for person must receive either the Dependency Supplement or the allowance for assistance to a third person in order for the caregiver to be recognized by the Statute; the extinction of the terms “primary” and “secondary” caregivers, being replaced by “full-time” and “part-time” caregivers; the right of caregivers to a minimum of 58 working days of rest per year; the exemption from the payment of fees in the National Integrated Long-term Care Network, when this is intended to ensure caregiver's rest; an increase in the amount of the informal caregiver subsidy for full-time caregivers, corresponding to 100% of the value of the contributions levied at the first level of voluntary social insurance; the elimination of the means test for the support subsidy; and lastly, job protection for part-time informal caregivers, ensuring absence arrangements, leaves, flexible working hour regulation, and the extension of the initial parental leave to up to one year for those recognized as carers. On top of this, for NAIC, two other fundamental measures to improve the quality of life of caregivers, and which are yet to be enforced by the

Statute are: 1) the existence of a healthcare professional of reference, that would monitor caregivers' basic needs and be responsible for giving them training; and 2) the existence of free home-based assistance.

### **7.3.3. The Perceptions of the Portuguese Political Parties**

Regarding political parties' perceptions of support for informal caregivers, not much has changed compared to the draft Laws discussed in 2016, 2018, and 2019, before the implementation of the ICS. In fact, one of the only major differences is the parliament's constitution, with CDS-PP and the Greens (PEV, left-wing party) losing all of their representation, and three new parties gaining seats: *Livre* (L, left-wing party); *Iniciativa Liberal* (IL, right-wing party); and *Chega* (CH, far-right wing party). Additionally, PS now governs with an absolute majority, leaving behind its colligation days with BE and PCP, which were fundamental to the approval of the Statute. This majority, as we will see, was all it took for PS to begin displaying indifference towards the informal caregivers' fight, as evidenced by their unwillingness to submit a proposal regarding them in the past four years. Despite this, it remains interesting to assess whether other parties' voting behavior and their stances on the care sector have undergone any changes.<sup>22</sup>

Commencing with PSD, the party's core principles remain largely unchanged. An aversion to institutionalization persists within the party's dialogue (draft Resolution no. 759/XV/1, PSD, 2023a), as well as an eagerness to leave the task of providing care services to the private sector. This ideological approach is reflected in draft Law no. 815/XV/1 (PSD, 2023b), which states that the general lack of care services in the country can be solved by entering into more social concertation agreements with the third sector. PSD states that: "The government should expand the number of vacancies and social beds, through the co-operation system, by contracting in the private network, (...) or through private facilities licensed for the purpose, which include those run by commercial companies, sole proprietors, or legally equivalent licensed IPSS" (PSD, 2023b, p. 6). In this scenario, the State would only have to update the co-payments already granted to these institutions (deemed insufficient at the moment) according to their real cost value, considering the current socio-economic situation (inflation), and the extent of territory and population covered (draft Resolution no. 758/XV/1, PSD, 2023c). This would not only correct the chronic underfunding of the third sector, but would be beneficial for all its beneficiaries, as new services would be created, and old ones expanded. (Draft Resolution No. 299/XIV/1, PSD, 2020b; Draft Resolution No. 304/XIV/1.<sup>a</sup>, PSD, 2020a).

The other two right-wing parties in parliament, IL and CH, are unsurprisingly aligned with the PSD's approach to care, as they share the same market economy values. However, apart from voting in favor of

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<sup>22</sup> Due to no longer having political representation in parliament, I will refrain from analyzing CDS-PP and PEV's proposals.

the aforementioned proposals, they have not developed many of their own, and those that they have, are lacking in content. In its draft Resolution No. 256/XIV/1.<sup>a</sup>, IL argues for a revision of the “Strategic Plan for the Development of Palliative Care” so that it begins to correctly assess national resources and foment a universal network (IL, 2020). No more guidelines were given to the government. In the same way, CH presented two draft Resolutions in parliament, both calling for the creation of a national program to expand the offer of geriatric residential facilities (draft Resolution no. 389/XV/1.<sup>a</sup>, CH, 2023a; draft Resolution no. 117/XIV/1.<sup>a</sup>, CH, 2021). In what way, it is not known. Also interesting to note, is that in draft Resolution No. 117/XIV/1.<sup>a</sup> (CH, 2021, p.1), the party states that “it is also important that the government makes it one of its priorities to support the elderly and their families, *enabling their children to take care of their parents*, thus improving their quality of life and saving scarce public resources”. In a proposal where the main objective is to increase care infrastructures to, I assume, relieve informal networks, it is interesting to note how the party mentions that the State should continue to foster their existence.

The left-wing parties under analysis, on the other hand, look at solving the care crisis from a different perspective. While the fight and defense for the expansion of social responses is also one of their priorities, for them State investment must be implemented differently. Instead of investing exclusively in institutions of the third sector, these parties think it would be better to invest in the creation and development of existent public service networks, transposing the role of the State from that of a simple investor, as advocated by right-wing parties, to that of a regulator, a structurer of the care sector. Hence, PCP, BE, and PAN have presented proposals and resolutions to ensure just that<sup>23</sup>. PCP proposed the design of a Public Network of Residential Facilities for the Elderly (Draft Law no. 819/XV/1.<sup>a</sup>, PCP, 2023a; Draft Resolution no 262/XV/1.<sup>a</sup>, PCP, 2022a) in which new vacancies in care services would be created through public management, by the utilization of unused social security equipment and unoccupied State-owned buildings. In this way, for the party, there would be an enlargement, requalification, and quality improvement of social responses for the elderly, that would no longer be fated to illegal nursing homes, extensive waiting lists, and lengthy hospitalizations due to lack of social responses. To complement this, new workers would be recruited, given formation, and paid a decent wage, representative of the importance of their work (PCP, 2022a). However, for the party, the development of residential structures for the elderly would have to be coordinated with home-support and daycare centers, to avoid unnecessary institutionalizations.

Also from this perspective, PCP presented in Parliament Draft Resolution No. 766/XV/1.<sup>a</sup> (PCP, 2023b), which argues for the development of the Nacional Network of Integrated Continuing Care (NNICC), which, due to a lack of resources, is unable to provide access and adequate care to its patients. This would be accomplished by hiring more health professionals (from different fields, to form

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<sup>23</sup> Livre has not put forward any proposals regarding this. Nonetheless, it always votes in line with the other left-wing parties.

multidisciplinary teams) and, as mentioned in the above proposal, utilizing unoccupied government buildings to create new units. Regarding the National Network of Palliative Care (NNPC), the party presented the same solutions (Draft Resolution no. 253/XIV-1.<sup>a</sup>, PCP, 2020a), adding a measure of direct support to caregivers: the permission, when possible, of the institutionalization of non-complex palliative patients in Residential Structures for the Elderly when their caretakers need time off to rest. BE presented a similar proposal (Draft Resolution no. 291/XIV/1.<sup>a</sup>, BE, 2020a), arguing for the increase of beds, capacitated professionals, and, consequently, teams/units in the NNICC and the NNPC. Like the left, PSD also urges for an increase in human and material resources, as this would result in a reduction in social hospitalizations (draft Resolution no. 800/VX/1.<sup>a</sup>, PSD, 2023d; draft resolution no. 304/XIV/1.<sup>a</sup>, PSD, 2020a). This investment, however, would necessarily have to encompass the entities of the social economy.

In addition to this type of measures, more focused on the Portuguese care network, various parties have also proposed bills geared towards offering direct or indirect assistance to caregivers. Regarding indirect support, measures are usually directed at individuals with disabilities, chronic or serious diseases, cancer patients, and the elderly. A great source of help for these groups is the Medical Certificate of Multipurpose Disability (MCMD), a document that indicates the degree of disability an individual has, as it allows them to receive the Social Inclusion Benefit (SIB), alongside with other social and fiscal benefits. To obtain this certificate, individuals must request a disability evaluation from a medical board. However, this board's assessment can take up to two years to respond, an inconceivable period of time. To solve this problem, PSD presented a proposal arguing that it should be ensured that medical boards be carried out within 60 days of the date of submission of the request for the assessment of incapacity (Draft Resolution no. 699/XIV/2.<sup>a</sup>, PSD, 2020b). BE and PCP also made this recommendation (Draft Law no 309/XV/1.<sup>a</sup>, BE, 2022; Draft Law no. 392/XV-1.<sup>a</sup>, PCP, 2022b), with BE adding to this the possibility of the validity of these certificates be done only by presenting proof of request for a medical assessment or reassessment, thereby cutting out long waiting periods. Additionally, in the cases where individuals are granted a degree of incapacity of 60% or above, the MCMD is automatically issued. This last measure also appears in PCP's proposal (PCP, 2022b), which complemented it by arguing for the gratuitousness of these requests in medical boards. On top of this, in the cases where the degree of incapacity of individuals remains stagnant, the MCMD should be automatically renewed, with medical boards not being needed. CH agrees (Draft Law no 246/XV/1.<sup>a</sup>, CH, 2022).

Still regarding the MCMD, another support measure was proposed by PSD (Draft Law no. 674/XV/1.<sup>a</sup>, PSD, 2023e): the immediate payment of the SIB from the moment users require the MCMD, as long as they present proof of the request for the certificate or the appeal for the assessment of disability before a medical board. This would ensure that while users wait for the medical board's assessment, they would at least be supported by the SIB without losing retroactive payments. Both PAN, L, and PCP (2) made equal proposals

(Draft Law no. 774/XV/1.<sup>a</sup>, PAN, 2023a; Draft Law no. 779/XV, L, 2023a; Draft Law no. 768/XV/1.<sup>a</sup>, PCP, 2023c; Draft Law no. 545/XIV/2.<sup>a</sup>, PCP, 2020b), with PCP furthering theirs by alleviating the benefit constraints, making it possible for (some) individuals with a degree of disability below 60% to take advantage of it, as well as to individuals that gained a disability over the age of 55 due to an accident, and not old age, to apply. This alleviation was also proposed by BE in Draft Law no. 776/XV/1.<sup>a</sup> (BE, 2023a) and Draft Law no. 571/XIV/2.<sup>a</sup> (BE, 2020b).

Measures encompassing exclusively the elderly are also not lacking. While PAN argues that the Solidarity Supplement for the Elderly (SSE) should never be less than the poverty line (Draft Law no. 769/XV/1.<sup>a</sup>, PAN, 2023b), CH and L advocate that invalidity and old-age pensions should be updated regarding the fluctuations of the Consumer Price Index (Draft Law no. 703/XV/1.<sup>a</sup>, CH, 2023b; Draft Resolution no. 478/XV/1.<sup>a</sup>, L, 2023b). On the other hand, BE and PCP (Draft Law no. 521/XIV/2.<sup>a</sup>, BE, 2020c; Draft Law no. 567/XIV/2.<sup>a</sup>, PCP, 2020c) claim for the families' income to not be considered for receiving the SSE, since this excludes a lot of elderly from eligibility.

These drafts, if voted favorably in parliament, would represent a source of indirect help to informal caregivers, who would greatly welcome these new fonts of financial support. Concerning direct social support, the increase in the amount of subsidies, the strengthening of employment protection, the right to free/affordable home care, and the carers' right to rest are some of the proposals put forward by the political parties, regardless of their ideological spectrum (PCP, BE, PAN, PSD, L). However, many of these are still being tailored only for parent carers (of young children), leaving all other caregivers unprotected.

To complement direct monetary transfers, politicians are aware that caregivers should also have access to quality formal services of care. In this way, PCP proposes the extension of home care services to every day of the week, whether they belong to the public or private network of care (Draft Resolution no. 262/XV/1.<sup>a</sup>, PCP, 2022a). These services should include nursing care, physiotherapy, psychosocial support, household chores, and assistance with hygiene needs. PSD agrees, furthering that home care assistance should also be available at night and on holidays, and provide telecare, patient transportation, cognitive stimulation services, and 24/7 monitoring and surveillance services (Draft Resolution no. 759/XV/1, PSD, 2023a). On top of this, PSD also argues for a) the creation of a telephone helpline for patients and informal caregivers making use of palliative care, coordinated by capacitated nurses; b) the creation of a "patient manager", responsible for accompanying palliative patients throughout their illness, as well as to interconnect health and social security services; c) the existence of a priority service for informal caregivers in health services, social security, and tax authorities; d) the creation of economic incentives for palliative care teams to accept more patients, thereby ensuring the possibility of caregivers to enjoy periods of rest, free of charge; and, lastly, e) the creation of reintegration labor market measures (Draft Resolution no. 304/XIV/1.<sup>a</sup>, PSD, 2020a).

However, the most important direct measure that could have the potential to increase caregivers lives if implemented correctly, has been the ICS, since it agglomerates several support policies within itself. Nevertheless, as has already been stated by informal caregivers and the NAIC, the flowers of this initiative have not borne fruit. At least not yet. With this in mind, PAN presented Draft Law no 820/XV/1.<sup>a</sup> (PAN, 2023c), in order to try to make the Statute more effective, covering a wide range of boxes. First, it eliminates two constraints found in the ICS, which are mentioned by caregivers as a cause of frustration: 1) the cohabitation clause, which impedes individuals who do not live with their dependents from being denominated as primary caregivers (and consequently from receiving the informal caregiver allowance); and 2) the limitative definition of who a carer is in the eyes of the law, that excludes non-family members from the mix. In this sense, PAN proposes new definitions for primary and secondary informal caregivers. The primary carer becomes “anyone who accompanies and looks after the person being cared for on a permanent basis, and who, as a result of this care, does not receive any remuneration for their professional activity or for the care they provide to the cared-for person” (PAN, 2023c, p.5). While secondary carers “are those who accompany and care for the cared-for person on a regular but not permanent basis, and may or may not receive remuneration for their professional activity or for the care they provide to the cared-for person” (PAN, 2023c, p.6)

These classifications not only guarantee that a larger number of caregivers can apply for, and receive the statutory allowance, but also expand the range of individuals who qualify for ICS recognition. However, the draft’s proposals do not stop here. Following the aftermath of the passage of the Decent Work Agenda (*Agenda do Trabalho Digno*) (DRE, 2023), which entered into force on May 1<sup>st</sup> 2023, PAN proposed the following rectifications: a) concerning the possibility of teleworking for informal caregivers, which the agenda allowed for a maximum duration of 4 years, consecutive or interpolated, the party counterpointed this with an indefinite timeframe. Teleworking should only cease when the care provision itself comes to an end; b) furthermore, in cases where carers are forced to reduce working hours due to caregiving it is their right to resume full-time work when care ceases; and finally, c) also encompassed in the agenda is the right of carers to take advantage of an annual leave of 5 working days, which must be used consecutively. The downside of this legislation is that carers are required to give their employers 10 business days’ notice of their intent to use the license. For PAN, this notice is excessive and renders the measure unfeasible. Hence, it argues for a notice period of only (at least) 3 working days (PAN, 2023c).

In addition to this, BE presented Draft Resolution No. 768/XV/1.<sup>a</sup> (BE, 2023b), arguing for a revision of the ICS according to the CLI demands, advocating the regularization of precarious employment situations, by offering informal caregivers contracts and social protection. On top of this, the creation of a National Care Service was also recommended. While PAN and BE proposals were not adopted, perhaps because they were too ambitious, PSD draft Law no. 816/XV/1<sup>a</sup> was, as it had a much lower level of

demands (PSD, 2023f). This, of course, does not deem it any less important. Through it, the scope of individuals eligible for the recognition of the ICS has been expanded, namely to include non-family members. This inclusiveness, however, is not new, and had already been anticipated by BE, PAN, and PCP in earlier proposals (draft law no. 801/XIII/3, BE, 2018; draft law no. 820/XV/1<sup>a</sup> PAN, 2023c; draft law no. 804/XIII/3, PCP, 2018). In addition, this draft law also made it possible for family caregivers who do not share tax residence with their care recipients to assume the role of primary carers, thus becoming eligible for the informal caregiver subsidy (if all other conditions are met). The main difference between this proposal and the one presented by PAN is that it removes the cohabitation condition only for family members, which prevents non-family carers from also receiving the informal caregiver allowance. In this way, this measure is more restrictive than that of PAN.

Even with this level of restriction, the passage of this bill can be considered a victory. Since 2022, none of the proposals analyzed has been implemented, entirely due to the refusal of PS to vote favorably.

#### 7.4. Similarities and Differences

After all three of these perspectives, similarities were bound to happen. Table 3 summarizes them.

*Table 3 - Differences and similarities between the 3 actors*

| POV of CGS   | POV of NAIC                      | POV of Political Parties  |
|--|----------------------------------|---|
| Rest days for carers   | Rest days for carers             | Rest days for carers (BE) (PAN) (PSD) (PS)  |
| Capacitation of carers   | Health professional of Reference | Capacitation of carers (BE) (PAN) (PSD) (PCP) (PS)  |
| Affordable formal care services  | Affordable formal care services  | Time spent as a carer to count for retirement purposes (BE) (PAN)   |
| Paid leaves  | Cost-free home-based assistance  | Unpaid Leaves (BE) (PAN)  |
| Health professional of reference   | Reformulation of the IC subsidy  | Flexible working hours (BE) (PAN)   |
| Capacitation of health professionals   | Reformulation of the ICS         | Part-time (BE) (PAN)  |
| Increase in the value of the dependent's supplement and the assistance to the third person allowance |                                  | Increase in the value of the dependent's supplement and the assistance to the third person allowance (BE) (PCP) |
| Priority service for carers  |                                  | Priority service for carers (BE) (PSD) (PAN)  |
| Cost-free home-based assistance  |                                  | Access of carers to information regarding their rights (BE) (PAN) (PSD) (PS)                                    |
| Recruitment of more formal care workers  |                                  | Psychosocial support (PAN) (BE) (PSD) (PCP) (PS)  |
| Enhancement of social security staff's knowledge regarding carers' rights                            |                                  | Access to home-based assistance (PAN) (PCP) (PSD)   |
| Telework   |                                  | Reduction of working hours (PAN)  |
| Flexible working hours, without salary reduction   |                                  | Telework (PAN)  |
|  |                                  | Preferential conditions for access to early retirement (PAN) (PCP)  |
|  |                                  | Student carers benefit from a Student-Worker Statute (BE) (PAN)   |
|  |                                  | Access to continuous working hours (PAN)  |
|  |                                  | The existence of mutual help and support groups in the bereavement process (PAN)                                |
|  |                                  | Creation of a permanent helpline for Informal Caregivers (PAN) (PSD)  |
|  |                                  | Reinforcement and innovation of teleassistance technologies in the NNICC and home-care (PAN) (PSD)              |
|  |                                  | Creation of professional retraining programs for Caregivers to help re-entry into the LM (PAN) (PSD)            |
|  |                                  | Development and extension of existent formal care services (PSD) (CH) (IL) (PCP) (BE) (PAN) (L)                 |
|  |                                  | Recruitment of more formal care workers (PCP)   |
|  |                                  | Capacitation of formal care workers (PCP)   |
|  |                                  | Recruitment of more health professionals (PCP) (BE) (PAN) (PSD) (L)   |
|  |                                  | Capacitation of health professionals (PCP) (BE) (PAN) (L)   |
|  |                                  | Family caregivers (BE)  |
|  |                                  | The creation of a National Care Service (BE)  |
|  |                                  | Reformulation of the ICS (BE) (PAN) (PSD)   |



## Discussion of the Results

### 8.1. Informal caregivers: a Characterization

Several conclusions can be drawn from the analysis of the empirical data presented. Although only representing a small window into the reality of informal care in Portugal, this sample clearly shows the gendered reality of unpaid reproductive activities in the country, which is in line with the existing literature on the subject, which states that women tend to be the primary carers in society, regardless of their age, educational background, and affiliation with the cared-for person (Gil, 2021; Soeiro et al., 2020; Ehrlich et al., 2020; Naldini et al., 2016; Rummery & Fine, 2012). Nevertheless, this does not alter the fact that informal caregivers tend to be middle-aged (Naldini et al., 2016), with a life already made, that see themselves, most time, having to give it up to provide care. Besides their social lives, which tend to disappear over time due to a lack of formal support, their professional lives also severely suffer. The analysis showed that reducing work hours is usually the route most caregivers end up taking to try to manage both the private and public realms of their lives. These results solidify what other scholars had already testified: that the impact of caregiving on employment tends to be intensive, with caregivers being able to maintain their link to the labor market in most cases (Ehrlich et al., 2020; Van Houtven et al., 2013; Da Roit & Naldini, 2010; Spiess & Schneider, 2003; Naldini et al., 2016; Wolf & Sold, 1994). This partial remanence, although not as destructive as permanent labor market abandonment, still presents itself in the form of future opportunity costs, with caregivers eventually having to face pension cuts.

This intensive effect, however, depends a lot on the employment situation of caregivers (if they are self-employed or not), on the availability, affordability, and extension of formal and/or informal networks of help, on the degree of dependency of the care recipient, and on their geographical positioning. This last factor is deemed important since of all the interviews conducted in the Madeira Autonomous Region (7), none of the informal caregivers reported opportunity costs. This is mainly due to the more flexible working hours that caregivers have on the island (either worked mornings, afternoons, or had the possibility of leaving early), and to the calmer life they have there – without long home-work commutes and traffic, which gives them more time to care. However, this does not imply that caregivers find it easy/possible to conciliate a healthy work-care lifestyle, at least not without the existence of informal and/or formal support. This reality was found in all 15 interviews. This answers one of the research questions proposed. Informal caregivers find it possible to conciliate paid work and caregiving, only when they can rely on the help of an external source, either a friend or a home-based assistance service. When this is not the case, and when labor protection laws

are inexistent (such as paid leaves, support subsidies, work hour flexibility, and telework), the merge of the public and private spheres is not viable.

Furthermore, and analyzing the educational variable, not only caregivers with low educational backgrounds fall victim to opportunity costs. Those with a Superior Education can easily prioritize their caregiving responsibilities (this is the case of CG3, with a master's degree, and CG5, with a bachelor's degree). This ends up providing partial support to the opportunity cost theory proposed by Kröger and Yeandle (2014) and Carr et al. (2018). Hence, the claims made by scholars (Crespo, 2007; Keck & Saraceno, 2010; Da Roit & Naldini, 2010) who argue that higher levels of education lead to lower labor market exits, due to increased salaries, are proven wrong. The existence of financial stability is not enough to prevent individuals from changing the direction of their careers, with emotional ties playing a significant role in the decision-making process.

This holds especially true for female caregivers, who not only tend to feel more emotionally responsible for a sick relative or friend (Ehrlich et al., 2020), but also face gender-related coercing, as patriarchal societal norms bully them into assuming intergenerational care responsibilities (Ehrlich et al., 2020). This reality is emphasized in countries where public formal institutional support is not at the reach of the population, forcing women to step up and endure the task. This scenario is particularly prominent in Portugal, a country that not only has a corporatist welfare State, not keen on offering universal assistance to its citizens, but that also harbors a strong influence from the Catholic Church, an institution that ensures that outdated gender-normative traditional values are kept alive. As a result, the idea that the responsibility of caregiving is a rightful burden of the family, to be passed on to others only in breaking-point situations (when the family is no longer capable of tending to the dependent), is deeply ingrained in the brain of Portuguese women. This “brainwashing” was clearly present in the way caregivers thought, as seen from their statements. From feeling like a failure for institutionalizing a relative, to resigning themselves to being carers, and submitting themselves to being unpaid domestic workers for male family members, the influence of religious culture on perspectives of reproductive activities is evident.

Regarding men, and although it is true that they can also be pushed into caregiving roles, gendered standards will always permeate their actions, favoring them. While a gendered caregiving pattern was not found, per se, in this sample, with the two men interviewed providing holistic care to their family members, studies (WHO, 2022; Eurocarers, 2021a; Keck & Saraceno, 2010) that reveal a strong inclination of men to only concern themselves with managerial tasks, leaving physical caregiving duties to women cannot be swept under the carpet. Something that could be added to this, found in this analysis, and that stipulates a clear gendered distinction, is the existence (or lack) of informal support networks. Unlike most of the female caregivers interviewed, who rarely had any help from their male peers, male caregivers had strong informal support networks in place, with the caregiving responsibilities almost always being divided among other

family members, usually women<sup>24</sup>, who entailed part of the care provision. This reality naturally cannot be forgotten, as it affects the course of their social and professional lives. In fact, when it comes to employability, the two men in this sample were able to retain their jobs, and will unlikely face future opportunity costs, as opposed to the women.

Moreover, and still regarding the existence of informal support networks, CG4<sup>25</sup> shed new light on the topic: the potential influence of caregivers' age on the availability of support. While it is true that older caregivers can also lack informal support, it is more common for them to have a friend, family member, or even a neighbor who helps them emotionally and with certain caregiving tasks. This might be a direct result of their insertion, from a young age, in a conservative society, where women were expected to nurture their loved ones. Intergenerational cohabitation probably also played a role in this context. On the other hand, caregivers from younger generations might not experience this same sense of community, camaraderie, and solidarity, since individualistic views, brought by the neoliberal agenda, have grown<sup>26</sup>.

Despite this, informal community support networks continue to be the only source of solace and help some caregivers can get. Some, because they cannot afford the cost of formal help; others, because they distrust of the services provided. Therefore, these services are quickly substituted by informal arrangements, that, while not 100% effective, tend to get the job done. This reliance, however, should not be fomented, as caregivers will continue to shoulder a responsibility that should be of the State's domain.

## **8.2. The State: The Reinforcer of Bad Behavior?**

On the other hand, the State, although showing interest in the issue, is not actively trying to promote caregivers' well-being. This lack of willingness to change the paradigm was stated by the NAIC, but even without their testimony, the government's inertia was plain to see. From legislation analysis to talking to caregivers, the absence of support is blatant. The first, clearly being in the scarcity of information regarding carers' rights, magnified by the unawareness of State officials to pass it through. An argument could be made that this is an intentional strategy. After all, when citizens are unconscious of their rights, the State reduces expenditure, saving money. Unfortunately, this "saving scheme" has a direct impact on the lives of those who care, who not only feel unsupported in their journey but also see their physical and mental health deteriorate. Despite this, even informed caregivers (which are few) do not reap the benefits offered by the State. The bureaucracy of the process, the delay in the allocation of resources, the rigid constraints to apply

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<sup>24</sup> In both cases, their sisters.

<sup>25</sup> The statement referred to is the following: "*I feel alone and helpless. There are not that many people. People of my age, 36, nobody is in my situation, so there is a situation where you do not get involved in the group. It is not that I only talk about this, I do not, but they are really people who have a different maturity than me, and I cannot keep up with them in bars, clubs, things like that.*" (CG4)

<sup>26</sup> Be that as it may, this inference can only be proved with more empirical data, not available in this dissertation.

for aid, and the very low monetary value of subsidies are just a few reasons that prevent that from happening. This is coupled with the fact that caregivers are usually individuals of a certain age, that lack the energy and skills to apply for help.

This same reasoning applies to the ICS. While its implementation in 2019 was groundbreaking and seen by the public as a possible light to erase the neglect caregivers had been feeling, it has not done much. The ignorance of its existence is great, and the misinformation even more so. Even caregivers benefiting from the Statute have misconceptions about it. The sole caregiver interviewed and recognized by the Statute confirmed just this when she argued that she was unable to receive the Informal Caregiver Subsidy simply because she did not share a tax residence with her father (the care recipient). This is not true. The main condition for obtaining such monetary support is to be a primary caregiver. The fact that primary caregivers are obliged to live with their caretakers is just a second constraint. The NAIC has been working tirelessly to reduce this misinformation. However, few caregivers are aware of the Association's existence: of the sample, only 3. It is thus clear that action needs to be taken by the government. Awareness campaigns are needed, and the revision of the ICS urgent, since its legal impediments reduce its potential (not to mention all its enshrined rights that are still not being implemented). Investments should also be made in the care sector so that better formal services can be provided to caregivers, hopefully at much lower prices.

### **8.3. What is Actively Being Done? Is Portugal Being Faithful to the EU Approach?**

The EU has endorsed the route of professionalization and non-institutionalization as the only feasible solution to the care crisis that has persisted for years in the region. The institution believes that recognizing and formalizing caregivers' work, through direct and/or indirect measures, is key to doing that. The analysis of legislative documents, previously done, reveals a strong commitment from the Portuguese government/parties to adhere to EU guidelines. The provision of direct and indirect subsidies, to acknowledge and compensate caregivers for their invaluable services, and the offering of training and counseling (as outlined in the ICS), are evidence. Moreover, the employment of family carers by the State (BE), and the possibility to pay taxes while providing care (BE, PAN), were also proposed, having had favorable votes from all left-wing parties except PS. The only proposal that remains to be recommended, which appears in EU guidelines, is the validation of caregivers' skills after caregiving. This measure would undoubtedly help many reclaim some financial independence, by enabling them to re-enter the care LM formally, after years of informally providing care. This step was given by one of the carers interviewed (CG2), who chose to transition from providing unpaid informal care to her husband to paid informal care to

a stranger. While in her case this arrangement was done part-time, as she was never compelled to exit the LM, for others, this might represent the only viable path to achieving independence.

Similarly, the approach of non-institutionalization, referred to as “ageing in place” (Wieczorek et al., 2022, p.145), is gaining traction. Both right-wing (PSD) and left-wing parties (PCP, BE, PS) advocate for community-based solutions. While this shift is favored by carers – as it bolsters their autonomy –, and governments – as it aids in cost containment –, it has its downfalls (Wieczorek et al., 2022; Zigante, 2018). It is important to consider that not all homes are equipped to provide high-quality care and that caregivers often lack the means to retrofit their homes accordingly. Two caregivers mentioned having small houses where wheelchairs could not navigate, while another found it difficult to assist her mother at home due to the presence of stairs. This reality needs to be considered in policy formulation.

A convergence of institutional and home-based support would be an optimal solution, combining the strengths of both approaches. Political parties appear to recognize the importance of not overlooking formal responses, emphasizing the significance of investment in the LTC sector, whether through private or public means.

#### **8.4. Party’s Ideological Differences: 2019 vs 2023**

With the exception of PS, which did not present any Draft Laws/Resolutions between 2019 and 2023 regarding informal caregivers, the other parties behavior shows a coherent and unchanging path regarding the future of informality in Portugal.

PSD remains determined to maintain a familialist approach to the care crisis (Araújo & Soeiro, 2021). The design of measures to aid the family coexists with the party’s willingness to leave the provision of care to them. While it is true that the party is also committed to having the State invest in the expansion and development of private formal care services, to offer caregivers more social responses, it would be dishonest to think that this does not arise from a desire to commodify the sector. The furthering of the care business, which has become increasingly profitable, could be one of the right-wing party goals. The prices practiced by these infrastructures, which ensure that the majority of caregivers are not able to access them, is a non-problem to the party, easily resolved by supply and demand, by the will of the market. Within this mindset, a continuous reliance on the collaboration and goodwill of caregivers is expressed, with the carer being seen as the State’s helper in managing the care crisis. These beliefs are shared by the IL and CH.

Completely opposed to this is PCP, that believes that care should not only be de-commercialized but a social responsibility of the State. In its proposals, the State always appears as the structurer of care provision relations, alleviating the family of this burden. For the party, strengthening public social responses is key to allowing caregivers to have a dignified life. While the party also recognizes the role of private social solidarity institutions in the provision of care, it argues that these responses should only exist as a

complement to the public sector. Regarding the ICS, its existence continues not to be supported by the party (Araújo & Soeiro, 2021). This can be assumed by the lack of revision measures proposed. Lastly, BE and PAN continue to battle for a hybrid way of looking at care in their proposals (Araújo & Soeiro, 2021), being joined by L. For them, only in this way will informal care be recognized as structural to societies, without there being a minimization of efforts to not further it.

## **8.5. The Revision of ICS and Implementation of Further Support Measures for Caregivers**

The prospects of implementing additional measures to aid caregivers may appear plausible at first glance, given the common ground between political parties and caregivers (see Table 3). However, the absolute majority held by PS has effectively thwarted such efforts. Why? One possible explanation could be the pursuit of cost containment, as evidenced by their rejection or abstention from all proposals aimed at enhancing State investment in both public and private care sectors. Likewise, the party does not endorse the reinforcement of labor protection laws or the augmentation of allowance values. If this majority is upheld in the next legislative elections (in 2026), it may compromise the rights of informal caregivers. Nevertheless, if measures are adopted in this scenario, they are likely to be of a familialist nature, such as the PSD bill no. 816/XVI/1.<sup>a</sup> (PSD, 2023f).

The partial revision of the ICS achieved through it, with the scope of recognition being widened to encompass non-family caregivers, is to be commended. The elimination of the cohabitation requirement for being designated as a primary caregiver, too. However, this revision is not sufficient. Non-family members continue to be excluded from receiving the informal caregiver subsidy when not living with the care recipient. In these cases, cohabitation is unlikely, which leads me to believe that this barrier is only a measure of cost containment. The elimination of the conjoined residence for individuals with no kinship ties would improve the potential aid given by the law. Nonetheless, even with this opening up, caregivers would still struggle to qualify for financial assistance, due to the means testing that exists in the allocation of resources. Therefore, while this bill furthered the number of caregivers recognized by the ICS, the increase in support did not: the subsidy is still out of reach for many, and its value continues to be unsuitable.

Besides this inadequate monetary help, the most important part of the ICS, i.e., the rights of caregivers, is still to be implemented. Changes have to be made. Ordinances created. Caregivers are not satisfied with the ICS. And they should not be. At this point, and through the perceptions of NAIC, CG4, and CG7, it is clear that the Statute is not efficient. The perceived impact of the document on caregivers' lives is null, being only a piece of paper. This answers another proposed research question. The existence of this social support, from 2019 until now, has not benefited caregivers. Furthermore, another flaw of the ICS is its

failure to correct gender inequalities related to caregiving, with a gender-positive discrimination perspective being missing in the document. Leaves especially tailored for male caregivers could be part of a solution to help redistribute care responsibilities among the family, ensuring that gender equality would be enhanced. The gender variable has to be on the table since it is women that face the consequences of upholding the sustainability of the formal care sector on their backs. It is also women who endure opportunity costs (Araújo & Soeiro, 2021), something that cannot be forgotten in policy making. The sexual division of reproductive work has to be considered.

## **8.6. What Measures Should be Implemented?**

Numerous measures can be taken to offer assistance to caregivers both during and after their caregiving journey. Based on the insights gathered from the interviewed caregivers, the following recommendations emerged: 1) their capacitation, so they can provide better care to their loved ones; 2) the appointment of a health professional of reference, to address their questions and offer crucial support during challenging times; 3) the availability of carers' respite; 4) the existence of priority attendance for carers in certain services, to minimize the time their dependents spend without supervision; 5) the increase in the value of existent subsidies; 6) the creation of paid leaves, to help caregivers maintain their attachment to the LM; 7) telework; and 8) the possibility of working flexible hours without salary loss. If implemented, these measures would undoubtedly enhance the quality of care provided by caregivers. However, they should exist only as a complement to accessible, high-quality formal care services, so that informal care is not fomented, and caregivers are given a choice.

While it is clear that the public solutions given to the population are lacking and deeply underfunded, and that the semi-private ones are not effective due to economic barriers, the government is not actively trying to reform the system. The almost complete monopoly that private catholic institutions have on the provision of care services in Portugal is in sight. Only when all the dimensions of care are seen by the State as fundamental to day-to-day life, will public responses gain weight, and the policies implemented will stop addressing the issue through the externalization of care to the third sector, – that is happy to ensure that these policies remain in force. Unfortunately, while that reality might still be distant, the only role played by the State is that of a funder, as well as a regulator of the actions of the private solidarity sector, through cooperation agreements (Soeiro et al., 2020).





## CHAPTER 9

# Concluding Remarks

The demographic challenges Europe is facing, coupled with a lack of investment in the public care sector, have given rise to a care crisis that has been impacting the region for some time. Portugal is one of the European Member States more affected by this, as it has one of the highest percentage of elderly population in the EU. As a result, LTC services are currently being pressured, as the demand for them has outstripped supply. In response, community care networks have risen to fill this gap, with informal care becoming the most resorted solution for families. It is therefore expected that the number of informal caregivers will continue to rise, as they replace State social responses. Nevertheless, their importance to society is yet to be formally granted, with caregivers' rights being forgotten most of the time. This happened in Portugal with the ICS, and it is likely to be happening in other countries.

Portugal fits in the implicit familialism model, and thus informal care has no option but to flourish. However, this substitution arrangement will not survive for long, as the demand for caretakers will surpass the availability of professional and non-professional workers. To battle this, the EU is actively promoting a formalization/recognition approach, pushing informal caregivers into becoming semi-professionalized co-workers in the care sector, and provide home-based services. Portugal's ICS is borne out of these international guidelines.

The Statute represented, in its early stages of implementation, a light at the end of a tunnel of informality and invisibility. It ignited in caregivers a renewed hope for the fight that had been happening since 2016, and a sense of purpose for the conquest of even more rights. That initial spark has now dimmed, leaving caregivers once again ensnared in a societal context where social justice still remains to be made. This dissertation gave a platform to caregivers to voice their discontentment and frustration with the current situation of informal care in the country. Aside from the NAIC, which has been very vocal about its displeasure with the document, caregivers had yet to share their points of view, which unsurprisingly align with those of the Association. For them, the Statute may not even exist, it goes unnoticed, it does not aid them in any significant way. Government action is needed in order to change this paradigm. In the same way, caregivers' employment situation was analyzed in this dissertation, with a focus on trying to understand if caregivers believe it to be possible to combine paid work with unpaid care work. As it became clear, they are skeptical of that ever being possible without the interference of other variables. Yes, a coexistence of public and private realms is possible, but only when caregivers have access to affordable formal care services (or informal, when these are inexistent), and flexible working arrangements. The degree

of dependency of the cared-for person is also mentioned, as well as the geographical location of caregivers in the country.

The future is uncertain for caregivers, but it need not be. Academic research has already provided a list of measures that can help carers live a dignified life, as well as the real effects of their implementation to informal care (fomentation or mitigation). For Portuguese caregivers, the best path would be for the government to assume a hybrid nature in terms of support, like BE, PAN, and L advocate. In addition to having the possibility of relying on public affordable formal care services, they feel other support measures should be in place, to encompass all dimensions of their caregiving journey. For their employment life, paid leaves, telework, and flexible working arrangements without salary loss; for their social life, the availability of carer's respite; for their physical and mental health, their capacitation, and the appointment of a health professional of reference; and for their financial lives, the increase in the value of existent support subsidies.

The research findings presented in this dissertation, although not groundbreaking, hold the potential to contribute to the “bigger picture” by furthering the fight for the improvement of informal caregivers' conditions in Portugal. This work aligns with literature advocating for increased public investment in the sector as the key to addressing the care crisis. While additional support measures should be available to aid caregivers – especially for elderly carers, that have a bigger difficulty in providing care and thus need more support –, they should be complementary to a comprehensive affordable public and transversal network of formal care services. All aspects of informality should be thoroughly considered in policymaking, yet governments appear to overlook certain variables in their decision-making process. Some to follow cost-containment policies, others, to foment the commercialization of care. Regarding the Portuguese case, this dissertation has real-world applications. The potential of this whole study lies in the perspectives and feedback of caregivers. Their daily-life struggles and suggestions, if truly taken into account, would “revolutionize” the Portuguese care sector, certainly improving their lives more than the ICS ever did (which is easy, since its application was faulty since day one).

Despite this, this dissertation has its limitations. The size of the qualitative sample, of only sixteen interviews in total, greatly reduces the viability of my findings, as it is clear that such a small sample can never truly and reliably represent the universe of informal caregivers in Portugal. Although generalizations cannot be made, this limitation does not deem this research any less valuable, as it can still contribute to giving visibility to a group, and theory formation, serving as the basis for future research. Furthermore, many dimensions of informal care remain to be explored. I make two suggestions: 1) further research could focus on the role of trade unions in the fight for decent flexible working conditions for caregivers (or their lack of willingness to join this struggle); or 2) research could focus on assessing whether younger generations' perspectives on caregiving, and experienced challenges, are shifting due to societal normative

transformations. Will informal care decline on its own as a result of these shifts? Or will the weight of a patriarchal conservative society continue to make itself felt in the way care relationships are formed?

Regardless of how we want to look at care, or which variables we deem important to analyze, all research should have in mind the centrality of this sector, interdependent with all dimensions of human life. Societies would not function without this invisible work. It is high time for governments to align policies accordingly. Yet, the quest for true social justice for (Portuguese) caregivers remains a distant reality, held back by entrenched familialist views. Systemic change is overdue, not only in the recognition of care's pivotal role but also in how we once took it for granted in our societies.



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# Appendix

## A. Interview scripts

### Informal caregivers

#### Part 1 – Informal caregivers characterization

1. How old are you?
2. What is your level of education?
3. What is your marital status?
4. What is your nationality and place of birth? (if you are a foreigner, how long have you lived in Portugal?)
5. What is the relationship between you and the person you are caring for? (Kinship? Friendship?)
6. How many people do you care for? Do you also have children at your care?

#### Part 2 – Elderly care/day-to-day family organization

1. How long have you been an informal caregiver?
2. What led you to become an informal caregiver?
3. What type of care do you provide to the care recipient? (Do you live with the care recipient? What is the degree of dependency of the cared-for person?)
4. How much time per day and per week do you spend providing care? Do you have weekends, holidays, and vacations to rest from caregiving?
5. What are the biggest problems you face in your daily life as an informal caregiver?
6. Do you feel that health professionals have provided you with the necessary training and equipment to know how to care for the dependent person in a home setting? (If not, how do you think they should prepare informal caregivers for this task?)

### Part 3 – Statal support

1. Did you find it difficult to find out about your rights when you became an informal caregiver? (If so, how do you think this information should be disseminated so that it becomes more accessible to new carers?)
2. Are you a beneficiary of the Informal Caregiver Statute? (If so, are you aware of the changes it has introduced? How have they affected you? Do you feel that there has been an increase in social support for caregivers?; If not, what restrictions prevent you from doing so?)
3. Do you receive financial support from the State? (If so, do you think it is sufficient to cover the costs of care? And to externalize care to formal services?; If not, why?)
4. Do you have income, both personal and/or of the cared-for person, sufficient to care for them?
5. Do you resort, or have considered resorting, to the help of formal care services provided by IPSS or *Santas Casas da Misericórdia*? (If not, why?; If so, do you think these services are sufficient and of good quality? What could be improved?)
6. In what context do you think your relative would benefit from better care: at home; in formal institutions, or in long-term care facilities?

### Part 4 – Professional path

1. Were you employed when you became an informal caregiver? (if so, did you have to leave your job involuntarily to provide care?)
2. Are you currently employed?
3. Do you think it is possible to combine paid work with caregiving? (If not, why? What measures do you think should be taken to make it possible?)

### Part 5 – Civil society

1. Do you know the National Association of Informal Caregivers?

### **National Association of Informal Caregivers**

1. Since 2016, the fight to dignify the work of informal caregivers has been debated more or less recurrently in the Portuguese political arena. This struggle eventually culminated in the

approval of the Informal Caregiver Statute in 2019, with the passage of Law 100/2019. How has this law changed the lives of informal caregivers?

2. Do you feel that the rights that have been achieved have fallen far short of the needs of caregivers?
3. As a representative of the National Association of Informal Caregivers, what measures do you think remain to be implemented in this Statute?
4. What would you say are the biggest problems faced by informal caregivers in Portugal?
5. Do you feel that informal caregivers are generally informed about their rights? For example, what government support can they apply for and how should they go about it?
6. Do you feel that with the adoption of the Informal Caregiver Statute there has been a greater visibility and understanding of the reality and extent of informal care in Portugal?
7. Do you feel that the government is more likely to implement and strengthen policies to support caregivers now than in 2019?
8. Since the creation of the National Association of Informal Caregivers in 2018, do you feel that you have been able to reach caregivers who might not otherwise have access to information? For example, through conferences, webinars, trainings.
9. You are currently drafting a bill to amend Law 100/2019 and the Regulatory Decree 1/2022. Can you tell me about this bill? How is the process of collecting signatures going at the moment?
10. Do you feel that you have the support of political parties in this fight, or is there a general lack of interest on their part?
11. Are you currently finding it easy to get in touch with these parties?
12. What are your thoughts on the creation of a National Care Service?