



# Being paid to care for or to care about? National report - Portugal

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## About ETHOS

*ETHOS - Towards a European Theory Of Justice and fairness* is a European Commission Horizon 2020 research project that seeks to provide building blocks for the development of an empirically informed European theory of justice and fairness. The project seeks to do so by:

- a) refining and deepening knowledge on the European foundations of justice - both historically based and contemporarily envisaged;
- b) enhancing awareness of mechanisms that impede the realisation of justice ideals as they are lived in contemporary Europe;
- c) advancing the understanding of the process of drawing and re-drawing of the boundaries of justice (fault lines); and
- d) providing guidance to politicians, policy makers, activists and other stakeholders on how to design and implement policies to reverse inequalities and prevent injustice.

ETHOS does not only understand justice as an abstract moral ideal that is universal and worth striving for but also as a re-enacted and re-constructed 'lived' experience. This experience is embedded in legal, political, moral, social, economic and cultural institutions that claim to be geared toward giving members of society their due.

In the ETHOS project, justice is studied as an interdependent relationship between the ideal of justice and its manifestation – as set out in the complex institutions of contemporary European societies. The relationship between the normative and practical, the formal and informal, is acknowledged and critically assessed through a multi-disciplinary approach.

To enhance the formulation of an empirically based theory of justice and fairness, ETHOS will explore the normative (ideal) underpinnings of justice and its practical realisation in four heuristically defined domains of justice - social justice, economic justice, political justice, and civil and symbolic justice. These domains are revealed in several spheres:

- a) philosophical and political tradition;
- b) legal framework;
- c) daily (bureaucratic) practice;
- d) current public debates; and
- e) the accounts of vulnerable populations in six European countries (Austria, Hungary, the Netherlands, Portugal, Turkey and the UK).

The question of drawing boundaries and redrawing the fault-lines of justice permeates the entire investigation.

Utrecht University in the Netherlands coordinates the project, and works together with five other research institutions. These are based in Austria (European Training and Research Centre for Human Rights and Democracy), Hungary (Central European University), Portugal (Centre for Social Studies), Turkey (Boğaziçi University), and the UK (University of Bristol). The research project lasts from January 2017 to December 2019.

## EXECUTIVE SUMMARY

This deliverable is part of the Work Package 5 “Justice as lived experience”. In the case of this specific deliverable, the goal is to understand (in)justice regarding persons with disabilities, with a focus on disabled adults and care workers. Looking at conflicts, tensions and contradictions between justice claims by persons with disabilities and the negotiation they made in their everyday life, injustices become visible. Although we sought to give voice to those who are considered ‘vulnerable’, we tried to avoid focusing in victimhood; rather the emphasis is placed on the capacities and agencies of persons with disabilities.

This deliverable aimed to address the following key questions: identification of the intersections and contradictions between what are the people’s understanding and experiences of recognition and redistribution and the theory of social justice; understanding what the practical and conceptual tools are used to negotiate justice claims; examination of the role played by the welfare state in creating conflicts and shared interests between care workers and care users, as well as the challenges and opportunities for justice in the context of home-based care; and finally the differences between the public and private spheres in terms of home-based care.

Being focused on relationships generated by care, in the work carried out in Portugal we opted to combine, in terms of methodological approach, mini-ethnographies and semi-structured interviews. The first method was selected with the objective of understanding the differences between theory and practice and to capture what is unsaid in terms of care. The second option served to specify details related with the observation and to grasp ideas that were not addressed or identified during the ethnographic observation.

One of the main findings of this research is that although the responses and types of care in Portugal have increased and improved over the last years, the welfare state continues to be mainly supported by the welfare society, that is, supported by the networks and relationships of solidarity between people and especially by the families.

However, even this welfare is in crisis. As a result of the financial crisis and to secure the economic stability, people work longer hours and can’t provide care for their relatives. In this context, families often rely on the help of commodified care, benefiting of the solutions proposed by the social security. What the research has shown is that even if the elders remain in their houses, the lack of investment in hiring more care workers means that care provided is not adequate. Physical care is undoubtedly guaranteed but the emotional side of care falls short of the expectations of both caregivers and care users; it is essentially to ensure the profitability of these services and institutions.

If the persons with disabilities / care users are dependent of the care workers, the latter are also dependent on the persons with disabilities / care users. Thus, we propose that the number of social responses available should be improved and, consequently the number of care workers, while avoiding the crowding of users. This option is fundamental to allow for the caregivers to dedicate more time and attention to each individual / person with disabilities. This could help both care users and caregivers to use their full capabilities and, at the same time, support diminishing the cases of burn-out of the care workers, the loneliness felt by persons with disabilities and the feeling of hopelessness expressed by both groups.

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## **LIST OF ABBREVIATIONS**

IPSS - Private Institutions of Social Solidarity [IPSS – Instituições Particulares de Solidariedade Social]

RSE – Residential Structure for the Elderly [ERPI – Estrutura Residencial para Idosos]

HSS – Home Support Service [SAD – Serviço de Apoio Domiciliário]

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## 1. INTRODUCTION

This national report contributes to Deliverable 5.3. The goal of this Deliverable is to explore justice claims in the lives of care users and those who are paid to provide care in private households, paying special attention to the role of gender. The analysis proposed by the Description of Work draws on considering people's capacity to achieve the life they value and their achievements.

Caring and being cared for is a human capability and a basic human need (Nussbaum, 1995 in Lynch, 2007) but care work is not fairly recognized or distributed between women and men. Indeed, as expressed by several scholar's care work falls on specific groups of women, often those with lower education levels or migrants. Being loved and cared are of central importance and this throughout all life (Lynch, 2007). Neo-liberalism and its assumption that all services are best provided through the market (Lynch, 2006 in Lynch, 2007) leads to the commodification of care work, overlooking the fact that unequal economic resources lead to unequal access to care and also to inequalities regarding who provides care. In Portugal one response to the problem of access to care was the creation of Private Institutions of Social Security (IPSS). IPSS were tasked with providing care to those in need and with few economic resources. It was intended that IPSS should work closely with the state. IPSS are private institutions that provide care for children, elders and persons with disabilities, providing social responses to those groups which are based on the types of care needs identified by the state. The care workers hired by those institutions are usually women with no training; they learn through practice how to provide care. Since they don't have the academic profile required by law to be recognised as workers, they are considered 'auxiliaries'.

In this report we present the results of the ethnography carried out in an IPSS located in a rural area of central Portugal. We accompanied two teams: one team from the Home Support Service, which provides home care, and the other a team that provides care in the nursing home associated with the HSS. In both cases we have identified unjust situations, mostly related to problems arising from the working conditions of the care workers which in turn have an impact on the care provided. In the words of the care workers, they cannot achieve satisfaction as they do not give the level of care they want. It's the willingness and feeling of moral obligation that encourages the care workers to provide the best care possible, putting their needs to one side. In several cases it was possible to identify situations of burn out. The care users / persons with disabilities recognize the effort made by the care workers, but they also would like to have better monitoring of their situation and to be followed more closely; loneliness is undoubtedly the most unfair situation referred to by the users, both those living at home and those who were in the nursing home.

This report is divided into four main parts. The first presents care in Portugal and the types of care available in the country, outlining the legal framework, including law and policy on care and private households, as well as the rights of the formal and informal caregivers. It ends with demographic national data and the presentation of the profile of caregivers based on an academic literature review. The second part describes the methodology. The third comprises the ethnography, which in turn is divided into two parts: an ethnography of Home Support Service and an ethnography of the nursing home. Finally, the fourth and last part comprises a discussion of the ethnography, some thoughts on comparisons, and the relation between the literature review and everyday struggles for justice.

## 2. NATIONAL CONTEXT

### 2.1. LITERATURE REVIEW

#### 2.1.1. CARE IN PORTUGAL

Care is closely associated with the social policies followed by a government. Portugal has a very specific kind of welfare state and social policies. The Portuguese welfare state divides its responsibilities between family (welfare society), the third sector and the market. As Boaventura de Sousa Santos puts it: 'in Portugal a weak welfare state co-exists with a strong welfare society', where 'welfare society' means 'networks of relations of mutual acquaintanceship, mutual recognition and self-help based on kinship and neighbourhood ties, by means of which small social groups exchange goods and services on a non-commercial basis and on a principle of reciprocity' (Santos, 1995:1). This is especially evident in the case of pre-school-age children, elders and persons with disabilities. The family has a great importance as caregiver of dependents, partly due to the fact that households can include three or more generations and a high percentage of people over 16 years of age still live with their parents. This puts considerable responsibility and pressure on family members to take care of dependent relatives whether they are elders, children or persons with disabilities. Families also have responsibilities in terms of sharing of income— social protection is organized on the basis of patriarchal families where men are 'earners' and the women the caretakers of family members (Esping-Andersen, 2000: 83 in Carvalho, 2005).

The history of extra-familial care in Portugal can be considered as beginning before XVIII century, when health care was secured by hospitals and religious associations (*Misericórdias*) (Rodrigues, 2014). In 1901, health care begins to be subject to a restructuration, with the state being responsible for providing health care for the poorest (Rodrigues, 2015). In 1945, the Law-Decree nº35/108, of November 7<sup>th</sup> created units to respond to specific public health problems (tuberculosis, maternal health, leprosy and mental health).

The creation of the Private Institution for Social Security (IPSS) marked a key development in the history of care in Portugal. These are 'non-profit institutions constituted by individuals, with the purpose of giving an organized expression to the moral duty of solidarity and justice between individuals. These institutions are not administered by the State'.<sup>1</sup> IPSS is a century-old reality in Portuguese society. Though they are sometimes known by different names one can find institutions of this type scattered throughout the country. For a long time, they were the fundamental instance of social protection. However, their role has evolved even as they maintain and even increase their range of activities. These changes have become particularly marked with the advent of social security, when the state assumed political responsibility for social protection, confirming rights and providing decentralised services. To guarantee these benefits the State used IPSS, regulating its activities and offering significant financing to guarantee these activities. This gave rise to a rather ambiguous status: the institutions 'felt' contracted by the state to provide services to the latter, while, at the same time, sought to maintain their own identity, rooted in civil society and independent of the state. It is not possible to quantify the economic contribution of IPSS in Portugal given the gaps still persisting in the

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<sup>1</sup> Our translation. Information available at <http://www.seg-social.pt/ipss>, accessed in June 2018.

collection and systematization of statistical information on this sector. Of the data available, the closest to the universe of action of the IPSS is the information on the so-called Non-Profit Institutions at the Service of Families (Sousa *et al*, 2012).

The relations between the state and the IPSS have been regulated by a set of very diverse legislative instruments, sometimes in a somewhat contradictory and dispersed way. The Portuguese Constitution and the Basic Social Security Law (Law nº83-A/2013) set the general institutional framework. Together, they recognize and structure the activity of organizations in the economic and social system as well as the provision of social action services. More specifically, the IPSS statute (Law-Decree nº172-A/2014) defines its objectives and nature, establishes the relations with the state and the rules for the creation, extinction and internal structuring of the various organizations. In 1974 new forms of intervention were introduced, characterized by giving a more central role to the state in the redistribution of income and in guaranteeing a social minimum to living standards. This quickly ensured the greater centrality of the state to social protection and a reduction in the contribution of private social protection, which until then had been provided by the Private Institutions of Assistance established during the fascist Estado Novo (Almeida, 2010).

There were several concerns regarding how to include the IPSS institutions in the field of social protection. The 1976 Constitution incorporated these types of organizations into the social security system. Article 63 (5) established that: '(...) the state shall, as laid down by law, support and inspect the activities and modus operandi of private charitable institutions and other non-for-profit institutions that are recognised to be in the public interest'. The introduction of the expression 'Private Institutions of Social Solidarity', was meant to cover Private Institutions of Assistance, in particular those identified to fill the purposes of the social security system, specified in the Portuguese Constitution in Article 63(3), namely the 'protection in sickness, old age, invalidity, widowhood and of orphans, as well as due to unemployment and in all situations of lack or diminution of means of subsistence or capacity to work'. Notably this overlooked institutions offering assistance in the area of health and housing. Nor could all organizations whose beneficiaries were their own members or associates, such as mutual societies, be qualified as private social solidarity institutions.

The successive constitutional revisions of Article 63 made some important changes. They came about as a result of a set of factors linked, on the one hand, to the evolution of the role of the state and, on the other, to the growing importance of IPSS' role in the provision of social welfare. On the side of state, the tendency was to complement the supply of public or quasi-public goods with private non-profit provision, following a contractual logic. On the part of the IPSS, represented by their unions, the interests focused on broadening their activities, and guaranteeing state support while, at the same time, they sought to strengthen their autonomy.

The evolution of the constitutional text clearly indicates the state's commitment to the implementation of a mixed economy in social welfare, although the role of IPSS is not always very clear. While the Constitution of 1976 recognized the role of so-called 'private social solidarity institutions', this type of organization was left out when three sectors of economic activity were (re)affirmed: public, private and cooperative. In the 1989 revision, the term 'social' was added to the cooperative sector, which became known as the 'cooperative and social sector' thus opening space for IPSS inclusion. The revision recognised 'the right of establishment of the private institutions of social solidarity'. In practical terms, this was the acceptance of the formal right for the IPSS to exist 'legally'.

The 1997 revision made further important changes. The references to IPSS, framed by section nº5 of the Article 63, emphasize the extension of their activities, which are no longer limited to the provision of Social Security, and broadened the meaning of the cooperative and social sector. As Article 82º describes, it includes ‘the means of production managed by non-profit-making legal persons whose main objective is social solidarity, namely entities of mutual nature’. These shifts seem to result more from the negotiating power of unions representing IPSS than from a clearer recognition of the role played by the third sector in Portuguese society. In fact, the Constitution did not clearly institutionalize the concept of the third sector, seeming to confirm Vivet and Thiry’s contention (2000: 42) that Portugal belongs to the group of countries where this sector (the ‘social economy’) does not have deep roots in society and is still at an emerging phase. It should be noted that the limited recognition of the third sector— both in terms of concept and practice — is not only manifest in the government’s positions but also in third sector organizations that do not see themselves as such. For this reason, therefore, it is not surprising that there is no unified institutional framework for it. Rather there is a vast set of very disparate laws, often incoherent, whose sum is not enough to form a policy.

In 1984, the first social security law of the post-25 April period was approved. Its tripartite structure consisted of a contributory scheme, a non-contributory scheme and social action. The social action component had (and still has) a role in filling gaps that the contributory and non-contributory schemes failed to meet. According to the text of the Basic Law of 1984, social action has a fundamental objective: to prevent situations of poverty, social marginalization and community integration. The law also specifies that social action is designed to ensure special protection for the most vulnerable groups, such as children, young people, persons with disability and the elderly, as well as other people who are economically deprived (Article 33). Like the non-contributory scheme, social assistance is financed through transfers from the state budget and develops in accordance with the law.

### 2.1.2. TYPES OF CARE

The Social Charter of 2015 (GEP/MTSSS, 2015) analyses and presents the types of ‘social equipment’ dedicated to caregiving in Portugal. They define ‘social equipment’ as: ‘all the physical structures in which different types of social assistance is developed or provided’ (GEP/MTSSS, 2015:7). As our fieldwork focus is on elder care we will present the services existing for this vulnerable group.

#### **Residential Structures for the Elderly (RSE)**

Residential Structures for the Elderly (RSE) or nursing homes are regulated by the Decree nº67/2012 of March 21th that promotes a more effective and efficient management of resources, including improved management of the quality and safety of physical structures, namely accommodation in different housing types and/or in rooms. The *Handbook of key processes regarding Residential Structures for the Elderly* (RSE) (ISS, 2014) recognizes that active and healthy aging means ‘the possibility of the person remaining autonomous and able to take care of him/herself in his/her natural environment’ (ISS, 2014: 3), but the number of elderly people who cannot live alone has been growing. Many of them have opted for accommodation with the RSE. RSE constitutes a ‘social response intended for collective housing, in a context of assisted living’, for persons of retirement age:

for persons at risks of losing their independence and/or autonomy, who by their own choice or due to a lack of a family/friend network and without dependencies caused by an poor state of health requiring continued or intensive medical care, intend to integrate into a residential organisation, being able to access biopsychosocial support services, oriented to the promotion of the quality of life and to the process of healthy aging, in an autonomous, active and fully integrated way. (ISS, 2014: 3)

Thus, the objectives of the RSE (Decree nº67/2012) are to provide permanent and adequate services to deal with the biopsychosocial problems of the elderly; to contribute to an active aging process; and to create conditions that preserve and encourage intra-family relationships and social integration. The principles followed are the maintenance of quality of life, a kinder approach to care and respect for individuality; full assessment of the resident's needs; the promotion and maintenance of functionality and autonomy; the participation and co-responsibility of the resident or legal representative or family members.

According to Article 5 of the Decree, RSE are intended for the housing of persons over 65 years old, who:

1 - cannot remain in their homes due to familiar reasons, dependency, isolation, loneliness or insecurity; [...]

3- The residential accommodation is also intended to provide accommodation in specific situations, resulting from the absence, impediment or need for rest of the informal caregiver.

The RSE delivers a set of services, namely:

- a) adequate food according to the needs of the residents;
- b) personal hygiene care;
- c) laundry;
- d) cleaning services;
- e) sociocultural, recreational and occupational activities aimed at enabling healthy relationships among the residents and for the stimulation and maintenance of their physical and mental capacities;
- f) support in the performance of activities of daily life;
- g) nursing care, as well as access to health care;
- h) administration of medication.

It is expected that the arrangements enable socialization, and facilitate relationships between the residents and those with the family and friends, the caregivers and the community itself.

## Day centres

A day centre is 'a social response, developed with adequate equipment, which aims to provide a set of services that contribute to the maintenance of the elderly in their socio-familiar environment' (Bonfim & Saraiva, 1996: 6). The objectives of day care centres are: a) provision of services that meet basic needs of the elderly; b) provision of psycho-social support for the elderly; c) fostering interpersonal relations of the elderly and of them with other age groups, in order to avoid isolation.

Day care centres are organized as stand-alone services with their own space, or as services integrated into other service provisions – nursing homes, community centres or other multipurpose structures. They provide: a) meals; b) cohabitation/occupation; c) hygiene care; d) laundry; e) group holidays. The principle rights of individuals using these centres are: a) to receive adequate support for their situation and to be part of the activities of the Day Centre; b) to participate in activities according to interests and possibilities; c) respect for identity, personality and privacy. The obligations users include: a) to comply with Day Centre rules; b) to participate, according to ability and interest in the activities proposed; c) to share the costs of the services provided, according to the law.

## Home Support Service (HSS)

These are:

a social response that consists in the provision of individualized and personalized care at home, provided to individuals and families when, due to illness, disability or other impediment, they cannot, temporarily or permanently, assure the satisfaction of their basic need and/or activities of daily living (Bonfim & Saraiva, 1996a: 7).

The general objectives of HSS are: a) to contribute to the improvement of the quality of life of individuals and families; b) to delay or to avoid institutionalization of the elder (Bonfim & Saraiva, 1996a). Authors<sup>2</sup> also specify the practical objectives of the HSS (Bonfim & Saraiva, 1996a: 7), which are: a) to ensure the satisfaction of basic needs of individuals and families; b) to provide physical care and psycho-social support to individuals and families, in order to contribute to their emotional equilibrium and well-being; and c) to collaborate in the provision of health care. The guidelines of the HSS explain that the service provide the following assistance to user: "a) hygiene and comfort; b) housekeeping and smaller cleanings; c) food preparation, as well as transport and/or distribution of meals; d) laundry" (Bonfim & Saraiva, 1996a: 8). HSS can also offer other services, including: accompany the user to do some errands; purchase of groceries and other articles; accompaniment, recreation and socializing; minor home repairs; make contact (by phone or mail) with the exterior if the user is not able to do it alone (Bonfim & Saraiva, 1996a: 8). It is taken as a firm general principle that the user's domicile is inviolable and should be considered as such, therefore care workers are not allowed to make changes or throw away goods and objects without prior authorization (Bonfim & Saraiva, 1996a: 9). In cases where the service/care provider has been entrusted with the key of the user's home, the key must be stored in a safe place or the care worker responsible must keep it under

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<sup>2</sup> The referred guidelines written by Bonfim & Saraiva (1996a) are under the responsibility of the Directorate-General of Social Assistance (<http://www.seg-social.pt/dgss-direccao-geral-da-seguranca-social>).

his own responsibility (Bonfim & Saraiva, 1996a: 9). In the event of death in the presence of HSS staff member, the HSS team must immediately inform a family member/guardian and must provide for the presence of a physician (Normative Dispatch nº62/99).

In the case of users in the HSS care network, there are various forms of payment. In the cases supported by Social Security, a percentage of the total cost is supported by public resources; another part is supported through the retirement pension of the elder. The values are always calculated based on the income of each person. In Alexandra's case, the care provided is supported by the elder's pension.

RSE, day centres and HSS are the three most common types social assistance available for elderly care. As well as supporting daily life activities they aim to promote inclusion and participation in the community, whatever the elderly person's degree of autonomy/dependence.

## **2.2. LEGAL FRAMEWORK**

### *2.2.1. LAW AND POLICY ON CARE AND PRIVATE HOUSEHOLD IN PORTUGAL*

The Constitution of the Portuguese Republic states that 'citizens with physical or mental disabilities fully enjoy the rights and are subject to the duties enshrined in the Constitutions, save for the exercise or fulfilment of those for which their condition renders them incapable' (Constitution of the Portuguese Republic, 1976 Article 71). Regarding elders, it specifically states that:

The elderly has the right to economic security and to conditions in terms of housing and family and community life that respect their personal autonomy and avoid and overcome isolation or social marginalisation; 2 – The policy for the elderly shall include measures of an economic, social and cultural nature that then to provide elderly persons with opportunities for personal fulfilment by means of an active participation in community life. (Constitution of the Portuguese Republic, 1976 Article 72)

In 1991, Portugal adopted the United Nations Principles for Older Persons.<sup>3</sup> In the same year, 'family hosting' was initiated to give the elderly an alternative to the family environment. This proposal was present as 'the most human and personalized response to the care of those group, avoiding or delaying as much as possible the use of the institutional response'. The idea was to integrate elders, temporarily or permanently into non-kin families considered suitable (Decree-Law nº391/91). Initially the goal was for the elders to be taken care by non-kin families in the house of the latter, a service paid to the household by the social security. The host families were to guarantee a socio-familiar and affective environment conducive to the satisfaction of their basic needs, respecting their identity, personality and privacy (Decree-Law nº391/91). During desk research little information regarding this initiative was found, being impossible to assess the success of it. Regarding institutions, in previous section (2.1.2.) types of care and their legal framework are described.

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<sup>3</sup> General Assembly Resolution 46/91, of 16 December 1991. Available at: <https://www.ohchr.org/en/professionalinterest/pages/olderpersons.aspx>. Accessed in April 2019.

### 2.2.2. RIGHTS OF CARE WORKERS

As a professional occupation, a 'care worker' is a person with formal qualifications, including physicians, nurses, and social assistants; the term 'care worker' indicates previous training specific to the professional activity they perform, although this activity can vary according to the context where they work (Rodrigues, 2014).

Sommerhalder (2001 in Rodrigues, 2014: 28) defines the formal caregiver as 'the person who provides services in care institutions'. This description better fits the cases analysed in our fieldwork, since the formal caregiver working both in the mobile units and in the nursing home are not physicians, nurses or social assistants. In fact, care workers are most of the times called 'auxiliaries'. Like any other worker, the formal caregivers/auxiliaries are protected by the general Labour Law (Law nº7/2009) that sets the rights and duties of workers. In some IPSS the administration defines the rights and obligations of the caregivers working in the nursing home (Barcelos, 2016). The formal caregivers that work within an institution can belong to trades unions from private or public sectors. The right of housekeepers hired by private households, not only as domestic workers but also to provide care for elders, have their right guaranteed by the Domestic work legislation (Decree-Law nº235/92). They support the elderly person in less intimate tasks: preparing meals, shopping, and keeping them company (Sousa & Figueiredo, 2002). This market is often informal; Portuguese workers are usually hired informally as substitutes for family carers. They can help provide emotional support and take care of the elder's transportation and financial management. There is also a status, the Family Helper, regulated by Social Security, (Segurança Social, 2015) but the most common type of commodified care work in private households is the one provided by the HSS (framed within the IPSS services) and the one provided by domestic workers.

### 2.2.3. FAMILY CAREGIVER

Elders often try to stay at home for as long as possible, seeking to manage their life independently. However, living longer lives often entails a longer period of fragility and incapacity which in turn requires care. In private households, care is mostly provided informally by family members. In Portugal, as all over Europe, family care is largely the responsibility of women; when it is wives who need care, husbands assume the care role, but they represent only 25% of family care (Sousa & Figueiredo, 2004), on those cases. In most cases, the care giver are the spouses (20%) or daughters/daughters-in-law (64,3%) of the dependent (Romão *et al*, 2007). Family caregivers don't receive directly cash benefits nor are they entitled to any other form of financial support for their role as caregivers. There are some possibilities of financial support such as the 'dependency complement' and the 'survival pension'. Those benefits are given to the person who needs care and not to the care provider. Due to the value of those benefits (minimum of 94,64€ and maximum of 189,29€, in 2019<sup>4</sup>), they do not cover, in most cases, the expenses related with care, nor do they compensate for the loss of caregiver's income.

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<sup>4</sup> Information provided by the Social Security website. Available at: <http://www.seg-social.pt/complemento-por-dependencia>. Accessed in April 2019.

In 2017, the Left Block, a party represented in the National Assembly, presented a petition to the Portuguese Assembly demanding the creation of the statute of the informal caregiver for persons with Alzheimer's disease and other dementias or neurodegenerative pathologies (Petition nº191/XIII/2ª). The petition demands the creation of this statute along with the creation of National Caregivers' Day and it calls for:

the establishment of the informal caregiver statute; provision of assistance to the caregiver (...); legislation that provides a reduction of 50% of working hours for family caregivers, without loss of income; strengthening support given to institutions that promote support, information, training and counselling for people with dementia and their caregivers (...); the development and diversification of the formal structures that can support patients and of structures that could substitute for caregivers through the strengthening of the National Network of Continuing and Integrated Care; supporting and promoting institutions that provide training to caregivers; creation of intervention teams in psychosocial rehabilitation; creation of help groups through local health centres and other institutions in the community; the development of an equitable tax system that promotes works in favour of caregivers/families; legal recognition of and payment of monthly cash benefits to family caregivers (...) after the death of the patient (this is intended to compensate for the loss of income arising from the previous provision of long term care for the dependent family member); legal recognition and the payment of cash benefits to family members after the death of patients with Alzheimer's or other dementias, as a means of compensation for the care given and to facilitate the reorganization of family life and professional reintegration into the labour market; in case that the caregiver is not yet retired, the months spent as caregivers must be considered as working months for retirements purposes", Petition nº191/XIII/2ª

This proposal is still under discussion in the parliament.

Although family caregivers aren't within the scope of analysis of this deliverable, in the case of Portuguese society, family care is a particularly pertinent issue. In 2018, the main carers of dependents continue to be the family; dependents (elders, disabled or others) are institutionalized only if absolutely necessary. However, with the financial crisis and its associated transformations, more and more families now opt to institutionalize their relatives. Many care institutions are reaching their maximum capacity; however, there is no evidence of the hiring of more care workers, suggesting a diminution in the quality of care provision, especially at the emotional level (see Part III).

## **2.3. RELEVANT AVAILABLE NATIONAL DATA**

### *2.3.1. NATIONAL DEMOGRAPHY*

In 2016 Portugal had a resident population of 10.325.500. Currently life expectancy is 82 years for women and 75 years for men. The ratio of elderly (65+) for every 100 young people was 7:148. There are about 1 million people aged 75 or over, of whom the majority are women (Ministério da Saúde, 2018). It is estimated that by 2050 Portugal will be the EU state with the fourth highest percentage of elderly people (25%). The results from a study conducted within November 2005 and April 2006

(Oliveira *et al*, 2010: 23) shows that the age group > 75 presents a functional dependence twice as high as other age groups. Men have a functional dependence 4,2 times higher than women. One fifth of the elderly who participated in the study spend eight hours a day or more alone.

Between 2000 and 2015, there was an increase of 72% in the capacity of the social assistance available, making a total of 111.000 new vacancies (GEP/MTSSS, 2015). In 2015, HSS was the provision system with the greatest capacity, with more than 108,000 vacancies,<sup>5</sup> representing one third of the total vacancies in social institutions for the elderly.

In 2015 there were 2700 HSS units and 2418 nursing homes and the availability of social assistance structures for elders in municipalities has been increasing. In 2015, 86% of municipalities had 10 or more social assistance structures available for people over 65 years of age. In the same year, 84% of nursing home users were aged over 75; 63% the users of the HSS had between 75 to 89 years and 62% of them had some degree of dependency. In the case of nursing homes, 80% of the elders are highly dependent, with most of the users remaining in the institution for at least 5 years (GEP/MTSSS, 2015: 44).

#### **2.4. PROFILE OF CARE WORKERS**

‘A professional who is paid a wage by the care recipient or by a care institution for which she works’ (Claassen, 2011: 45) – this is one of many definitions of a commodified care worker. However, as we witnessed during fieldwork, and as also evidenced in the literature, most of the formal care workers in Portugal are not professionals, that is, they aren’t physicians, nurses or gerontologists. These care workers are called ‘helpers’ or ‘collaborators’ of the institutions in which they work or, in cases of care workers hired in private households, they are considered ‘domestic workers’ and not care workers. Despite this official distinction, we have decided to use in this report the term care worker as an acknowledgement of the importance of their work and professionalism with which they carry, independently of having a diploma or not.

The typical profile of a formal care worker is a female (Reis & Ceolim, 2007), married, aged between 40 and 49 years (Colomé *et al*, 2011); with low education; most of them have worked for 7 years or more in the sector (Carneiro *et al*, 2009). Ferreira (2012) through interviews to 18 care workers, from both genders, working in an IPSS from the north of Portugal draw the profile of the workers that is similar to the one found during our fieldwork for this deliverable. As we observed during fieldwork, in most institutions there is an absence of training, which is a barrier to the quality of care, and Ferreira (2012) described this as one of the principal difficulties expressed by care workers. When questioned about the reason for choosing this profession, most of the care workers interviewed by Ferreira (2012) stated that it was necessary to ‘get a job’. Many had been placed in the position by state employment centres. Some also cited previous experience of elder care as a motivational factor. The institution where they worked was, for most, the place where they obtained their first professional experience as care workers. For the newly arrived workers, they will learn with their colleagues on the moment. Finally, another characteristic presented in the work by Ferreira (2012) that is similar to the

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<sup>5</sup> Places refer to the number of households/elders that can be helped in the context of the HSS.

cases found during our fieldwork is the importance of teamwork and collaboration among care workers. The interviewee of Ferreira research expressed that great importance of organizing the work between colleagues, and partnership especially regarding physical effort (Ferreira, 2012).

As the literature describes it is highly gendered work. The idea that (un)paid care responsibilities should be placed upon women is still shared by many people. In Portugal, all types of care work have always been highly feminised but before the 1970s the majority of women didn't work for a third person, but at home (domestic work, farm work and others). On the other hand, many women started working as domestic workers from a very young age, most of the times in a live-in arrangement which for many women was an opportunity to leave rural areas to go to the city or to be able to have a greater income and avoid working in agriculture (Wall, 1998 in Wall & Nunes, 2010). Today the nature of female employment has changed radically. Portuguese women work outside their home and full time. However, their care responsibilities didn't diminish, and for many families the solution has been to find a third person, usually another woman, to help with the 'domestic care'. In institutional/private settings, the demand for care helpers also reflects the ageing of Portuguese population and the increasing number of social responses needed to tackle the changes in demography (Wall & Nunes, 2010). Care work continues to be a sector dominated by national women, although as some researchers (Peixoto (ed.), 2006 in Wall & Nunes, 2010) suggest, in urban areas it is becoming one of the main areas where immigrant women find jobs. Baptista (2009) explained in his work that social security data showed that the percentage of foreign women working in the domestic sector increased from 7% to 11% between 2002 and 2006. We can say that, in more rural/traditional areas, it's a sector still dominated by Portuguese women.

### **3. METHODOLOGY**

The methodology for this case study followed the guidelines designed by the work package coordinators. The first part comprised desk research and involved a review of academic literature and the analysis of policy documents, legislation and demographic data regarding the Portuguese population, types of care and profile of care workers. This first review allowed us to obtain the background information necessary to carry out the fieldwork, that is, the second part of this case study.

The methodology chosen for the fieldwork was a combination of mini-ethnographies and semi-structured interviews. The ethnography is the basis for the fieldwork, as it was designed to observe, understand and explore the relationships between care workers and care users in private households. The semi-structured interviews were used to obtain more detail to add to the ethnographies, and particularly to add information that was not possible to obtain through the observations alone. In order to respect privacy, all names were changed and when someone was referred to by the participants and/or intervened their names were redacted.

The guidelines specific to the fieldwork were adapted because of difficulties with access. The aim was to observe commodified care relationships in the context of the private household to 'generate data on everyday practices of recognition and redistribution and how daily conflicts of justice claims are managed' (cited from the deliverable guidelines). We attempted several times using different contacts to find families/caregivers who would agree to participate in the study.

Unfortunately, the access was never easy: sometimes the relatives and parents of the care user were not willing to have someone 'strange' in their house; other times the care user did not agree to be observed in their intimate space. Therefore, in coordination with the coordinators of WP5, we agreed to adapt the field work: one field site was established through accompanying the mobile units of a Portuguese institution that visits dependent elders and provides home care. The goal was to compare this type of care with the care provided in a nursing home of the same institution.

This solution was found through personal knowledge and contacts with the caregivers of the institution, and were confident that the relationships in this context would be interesting to observe and analyse. The mobile units would enable us to observe situations where families preferred to keep the elder at home, avoiding institutionalization for the longest time possible whether for emotional or financial reasons and we could also observe situations where although at home, elders were left alone. In the nursing home we had the opportunity to see how individuals tried to recreate the life they had at home and fulfil the idea they had in mind for their retirement age. In both situations, the care workers were very important, as they provide not only physical care but also emotional care to the dependents. All care workers were Portuguese females, as the institutions do not employ migrant workers (Wall & Nunes, 2010). Taking care of older people in Portugal is mostly carried out by Portuguese women, and it is still very rare for men to work as caregivers partly for cultural reasons – women are perceived as the responsible for care provision – but also because most of the care users are women and they do not feel comfortable with men providing them with physical care.

Prior to the beginning of the observations and interviews, following the guidelines of ETHOS project, the letter and consent form was sent to CES ethical commission as well as the guidelines for us to obtain ethical clearance. After the formal authorization from the commission, the same documents were presented to the administration of the institution in which the fieldwork was done for them to also approve. Also, as demanded, for each individual participant the research study was explained and their oral and written consent was collected.

It is important to mention some limitations and discomfort felt with the fieldwork. We consider one week to be too short to observe the reality of the relationship between the caregivers and care users. Although we had authorization to perform the observation in the institutions, during the fieldwork we had to adapt to the schedules of the caregivers and their own will to participate in the research. The two first days of the fieldwork served to establish a relationship of trust between the researcher and the participant, which was not easy. Most of the caregivers felt observed and judged, despite the constant reassurance by us that they were not being evaluated on their work and that they should perform as they are used to do in their everyday working life. It became difficult to go unnoticed. One way to avoid this was to choose not to take notes during the observation, since it was clear that seeing someone writing was altering the behaviour and attitude of the participants. Care workers' lack of time and availability somehow compromised the development of the interviews, which were too short to really understand the key issues they felt regarding their profession. Regarding care users and their families, orally and written consent was given and no one refused the presence of someone who were not from the mobile unit's teams, since they assumed that the new presence to be a trainee/making an internship. However, they asked questions about the new arrival, in particular for how long the presence in the institution would last. In some cases, it was difficult to explain that the goal was to carry out a research. Personally, I (Laura) felt very uncomfortable being in someone home observing such intimate moments. Most of the time, I tried to stay outside the bedroom when

physical care was provided since it was the moment who caused me more discomfort. In my opinion, I didn't have the right to invade the intimacy of the people. During the observation in the nursing home, the discomfort was exacerbated due to the emotional demands of care users, who were constantly demanding my attention, and asking why I was there – in some cases, several times a day.

Although we understand and recognize the importance of looking at the private household as a specific site for claiming more redistributive justice, we do think that mini-ethnographies in this context gives a superficial overview of what can be the life of a caregiver and the life of a care user, and the claims for justice that could exist in the relationships of commodified care. During fieldwork we were able to tackle some of the themes that are common in those situations, but only the result of a longer observation could demonstrate the reality of these live experiences and certain problems that were probably diminished or ignored during the fieldwork.

## 4. ETHNOGRAPHY

### 4.1. HOME SUPPORT SERVICE<sup>6</sup>

In the Home Support Service where the fieldwork was carried out – Santa Casa -, I had the opportunity to accompany a team during the morning shift. These shifts take place every day, including weekends, from 8am to 4pm. A full shift normally includes a visit to about six houses located about five to ten minutes' distance from each other by car. I've chosen to analyse the case of António, however, I will also present some cases to represent the variability of cases that exist in the network of care as well as situations that caregivers must deal with.

António is 71 years old and lives alone. He has some mobility problems related to severe rheumatism. Since he lives alone, he is visited three times a day by the mobile units: morning, lunch time and late afternoon. The number of visits *per* day depends on the elderly familiar structure and his dependence degree. The lunchtime visit is the shortest and consists only in delivering the meal.

In most of the cases I observed during the ethnography, the care users could be left in the house unaccompanied and be safe. However, this is not always the case, and Antonio is left alone, but he does not necessarily stay safe. António stays in his house all day long, alone most of the time. Every day two out of the ten HSS care workers visit António and other users on that round. In the case of António the HSS are the only providers of care. As the working teams are constituted of several caregivers, I chose to accompany two caregivers in their work, Maria and Ana.

All the workers employed by the Santa Casa work for 40 hours per week. In the HSS there are two shifts: one that starts at 8h and ends at 16 h., with a break of one hour for lunch; the other shift starts at 16h and ends at 21h. It's rare that they alternate between shifts – there are two teams who work in the morning and two other teams who work in the afternoon. By law, they have the right to ten days off per month, and of those ten, two must be in a weekend.

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<sup>6</sup> All the names have been changed in order to maintain participants' privacy.

**TABLE 1: Number of caregivers working per shift**

Hours	Nº of caregivers on the 'North Round'	Nº of caregivers on the 'South Round'
8h – 16h	2	2
16h – 21h	2	2

**TABLE 2: Relationships of care (home support service)**

Context of care	Person	Description
Mobile care units	Care worker 1: Maria, aged 44	<i>Both carers have been working in the mobile care units for about 15 years.</i>
Mobile care units	Care worker 2: Ana, aged 35	
Mobile care units	Care user 1: António, aged 71	<i>Family is absent from home, António lives alone and has some mobility limitations. The mobile care units are the main carers and the home visits occurs three times a day – early morning, lunch and dinner/bed time.</i>
Mobile care units	Family member 1: Alexandra, aged 66	<i>Daughter whose mother (Inês, 82 years old) has mobility problems due to an accident. Since then they use the services of mobile care units. There is one person accompanying Inês during the day and another one during the night. The services of mobile care units are essentially for hygiene.</i>
Mobile care units	Member of the administration: João, aged 65	<i>João started working for the administration of the Santa Casa after retiring from his work in engineering. He is part of the administration since 2016 and has been trying some changes in the functioning of the nursing home, principally regarding the working hours of the carers.</i>

When I arrived at the nursing home, one of the caregivers of the nursing home told me to wait for Maria and Ana in the locker-room, announcing that the “help girls” should soon arrive. The official designation of the service is Home Support Service but in the institutions everybody, including the caregivers and the administrations refer to the team as “the helpers”. When Maria arrived, she told me to follow her to the locker-room where other caregivers were already preparing themselves to

start working while talking about the night shift. The locker-room is the space where caregivers from the nursing home and the mobile units are together, since they share it. In the table in the centre of the room was a notebook where the caregivers write what have happened during the shifts. The notebook (or 'book' as they call it) serves to inform the caregivers who will begin the next shift and to report to administration what happened:

In a normal, calm day, we write that 'there is nothing to register' and we take note of the medication that was administered. Sometimes, there are some problems, one elder is more agitated or hurt himself, didn't want to eat and we also must write that. [Maria]

After the caregivers change into working clothes they go to the main hall, where there is a large cupboard. It is in this cupboard that all the keys from all the houses in the HSS network are kept, stored in a small plastic box, inside a drawer. The keys are distributed depending on the round (north or south) that the caregivers will carry out – the distribution is made between them and there is no supervisor overseeing this task. Afterwards we went to the back of the building where the vans are parked. Three vans are normally used; however, since they only have two seats, Maria's team has to drive a five-seater van which is usually used to transport meals to the kindergarten. The employee in charge of the distribution complained that 'nobody told him' that he couldn't use the van during those days. Maria explained to him that 'the director didn't say anything to us about this either, but we can't go three in a two-seater van'. This situation exemplifies one of the main complaints of caregivers, which is that the management of conflicts between caregivers and other employees of the institutions is their own responsibility and is not overseen by supervisors. It seems that there is a grey area where no one is responsible for their acts, but at the same there is no one who will make the decisions for them. Given their experience, caregivers make decisions on their own and solve their own problems in the way they think is most appropriate, doing their best to always keep in mind the well-being of the users.

When we leave the institution, it is about 8.20. Between then and 10.17 we visit four other houses, which are visited every day always in the same order. When we arrive at Antonio's house he was already waiting for us. The house is in a small street parallel to the main road, and it is very dark with a lot of overgrown plants. When we get out of the van, the caregivers put on plastic gowns and gloves. When we approach the house, I can see that the garden is full of weeds and looks uncared for, in contrast to some of the houses we had previously visited. Before they open the door, Maria looks back and tells me 'Don't be scared'. They open the door and come in slowly, shouting 'António?', but there is no answer. They talk with each about the smell, that the house is dark, cold and damp. We continue down the hall. One of the care workers enters one of the bedrooms and the other goes into the kitchen.

I follow the caregiver who enters the room. Lying on a bed is António, who looks at me and comments 'One more?'. I explain that I'm accompanying the 'girls' during that week. He nods in agreement and doesn't ask any further questions about my presence. The caregivers begin the care routine, which is repeated by all the care users: first they positioned António on his back, they undress him and begin to wash him. First the hands, then the face. When it's time to start the intimate hygiene, I decided to leave to the hallway. When the cleaning is done, the caregivers help António get dressed. Throughout this process, Maria talks all the time with Antonio, asking if he slept well:

António: I slept only a little.

Maria: Why?

António: I didn't had feel sleepy... and I had nightmares.

Maria: About what?

António: Thieves. I dreamed of them coming to get the rest of the stuff...

Maria: Which stuff?

António: The stuff that is missing from the kitchen.

From the kitchen, Ana asks us if he's ready, Maria goes back to António, telling him to get up, so he can go and have breakfast. António pulls himself to the edge of the bed and Maria reaches out his arm for him to lean on. She encourages him to get up: 'Come on, you are lazy today?'. António laughs, but he must make some effort to move. Slowly they manage to reach the kitchen, and Ana has already set up the table with his breakfast: milk with bread, and she also has washed the dishes from the day before. António sits at the table and Maria puts medication on a spoon for him to take and leaves for the bedroom. I stay with Ana and António. While he eats, Ana talks with him about agriculture. Maria returns and comments to Ana: 'This smell is getting impossible'. Ana shrugs. António has to finished eating and they start to put the dishes away. They ask him if his sister has been visiting him, and he says no, that he hasn't seen her for a few days. Later, Maria told me that it was not just days but more like weeks. António gets up and walks slowly to the living room where there is a sofa and the television. Ana begins to collect the laundry and the garbage. Maria helps Antonio to sit on the sofa and installs him as comfortably as possible, his legs on pillows. She asks him if he wants her to turn on the television, he says yes, then she leaves him. I follow her; Maria and Ana are arguing about clothes. The latest instruction from the administration is to only take the laundry occasionally since the laundry of the institution is overloaded.

Ana: It's the orders we have...they said that they can't wash clothes during the day.

Maria: Do you really think that I will leave the clothes so dirty here? This house already stinks; we don't need to aggravate the situation.

They decide to take the clothes with them, despite being against 'the rules'. In each visit, the caregivers must sign a sheet which describes the care performed in each house and it's the last task they perform.

When we left the house, I asked what Antonio was talking about when he said that he was afraid of thieves. Maria explains that, as his health condition has weakened, the administration of the institution decided to take some measures for his safety. About a year ago, the mobile units were asked to lock most of the drawers, hide knives, lighters, matches and to turn off the gas when they leave the house.

António doesn't receive any visitors, and neighbours pay him little or no attention: 'He looks like an abandoned dog', Maria tells me with a certain pain in her eyes. 'The only people he sees during all day are the people from the help [that is, the HSS team]'. I ask about his sister, she explains that she doesn't know where she lives, she only knows that it is not nearby and she rarely or never visits her brother. They started hiding things for fear that he would hurt himself or cause an accident: 'His hands

shake a lot... and he has begun to be forgetful. If he leaves the oven on and there is an explosion... it's all the neighbourhood which will blow up'. I ask her what she thinks about this situation:

He should go to day care...Spending the day alone it's not good for him. There at least he would spend the day with other elderly people and the caregivers could look out for him. It's not that difficult...I don't understand why they don't make the effort.

She explains to me that the decision to take him as a day care patient is the responsibility of the institution. Usually, those elderly who are less dependent and have more mobility go to day centres, but they need to apply directly. In António's case, the Social Security could ask for his institutionalization in the nursing home, but 'there are few places, you know...and I guess he doesn't have a big pension...'. In case of financial needs, Social Assistance finances a proportion of the costs of institutionalization, but the demands are considerably higher than the places available, which means that there are many elderly people in their homes, who spend the day alone. Maria adds:

(...) we already had a similar situation! Mr. X, we would wake him up, do his hygiene every morning, then the van picks him up with other elders and at night we would come again to help him get washed and put him to bed. I don't understand why they don't make the effort for António... poor soul...

We arrive at another house which looks completely different from the previous one: it is big, bright and clean. It's the daughter-in-law of the care user, walking behind her, who receives us. The elder R. walks with the help of a walking stick. She says: 'Today it's bath day!', and everybody laughs. They go to the bathroom; the daughter-in-law explains that she turned on the heater, so the bathroom could get a bit warmer. Maria picks up a basin, the daughter-in-law asks if she doesn't want a bigger one, which makes Maria look at her confused. We hear R. saying, 'I'm not going inside the bathtub'. The daughter-in-law explains that R. is afraid of falling, 'even going to the toilet is complicated, she is scared that her legs will fail her'. Ana asks if something happened, but the daughter-in-law says that nothing happened, 'I don't know...now she's afraid and I don't want to contradict her'.

In the bathroom, they decide to give the bath outside the bathtub, starting by washing her hair. Ana exclaims to the daughter-in-law, 'You know we are going to make a mess...', but she responds that she doesn't mind. R. stands in front of the toilet and shouts: 'I don't want to fall, move the carpets away'. The caregivers fill the larger basin with water and sit R. on the toilet. They start to wash her as best as they can, as the old woman laughs and plays with her feet in the water. They dry and dress her, and R. ask if someone can dry her hair. She says that next week she will go to the hairdresser, but her daughter-in-law say that it's too early for that. R. says that she wants to be pretty for the party. The party is the baptism of her great-grandson, although the daughter-in-law comments again that it's too early for that. Maria notes that she is nervous because her daughter is going to get married and they are expecting rain. They talk about the preparations for the wedding, while giving some indication to R. on how she should move. In the end, they put the laundry inside the basin, this time they will not take it to the institutional laundry; rather, it will be daughter-in-law who will take care of it. They accompany R. into the kitchen and sit her down. The daughter-in-law arrives and says she'll make her a tea. The caregivers say goodbye and go back to the van.

This situation demonstrates the variability of situations that exist in the HSS network of care. Some, as we can observe with R., have family support and a house adapted to their needs, but there

are also several cases like António, where the financial situation doesn't allow them to be institutionalized in a nursing home and there is no monitoring by family members or other caregivers, and the care is restricted to the HSS teams.

At the end of this visit, we go back to the institution. It's nearly midday and the caregivers have the right to take a break. The teams get together in the main hall of the institutions to eat their snack and take coffee. They talk about their morning, if there was any problem with the care users. They all had a quiet morning. However, the case of António comes to the discussion, introduced by Maria:

Maria: António...that isn't life. There he was, left alone, it's terrible, it breaks my heart.

Caregiver 1: Yeah, we already know that, but what do you want us to do?

Maria: We have to talk! We have to signal the case/draw attention to his situation?!

The other caregivers shrug and change the subject. At 12.30, they get up and go back to the vans. There are carts with baskets near the door, with the care users' lunch. The carers begin to load the vans and they know by the name on the basket, which baskets go to which van. At lunch time there are three possible routes: 1) North round; 2) South round and 3) Round of the bedridden. As the name implies, round 3 consists only of care users who are bedridden and need help to eat. This is the round that takes more time because in some cases the care user needs to get their incontinence pads changed. As I wanted to observe the relationship of care with António in particular, I go only with Ana, since for round 1 and 2 it is expected to go only one care worker per van.

When we arrive at António house is in bed, Ana ask him why.

António: I was sleepy and cold.

Ana: Cold? Do you want me to put more blankets on the bed?

António: No, I think it's not necessary.

Ana encourages him go get up to go eat his lunch. Slowly, António goes to the kitchen and sits down. Meanwhile Ana has already put the food on the plate, served water and waits for him, impatiently, playing with the keys of the van. As soon as António sits, she puts the medication in his hand and tells him to drink some water. She then asks him if he needs anything.

Ana: I would go then. You can leave the plate there that the girls will take care of it.

António: OK then.

We leave the house; the visit takes no longer than 15 minutes. During the rest of the round, Ana explains to me that she has been working in the institution for over ten years and always on home support. I ask her opinion about António, about him living alone and seeing nobody besides them:

It's a big responsibility. We are the only people he sees all day, if anything happens, we'll be the ones to deal with it. There is no family, the neighbours don't care... it's difficult to know that we can arrive, and he can be hurt or... worse... we'll have the same fear, when we open that door, to not find him alive.

Once the round is finished, we return to the institution. It is lunch time for the employees. In the main hall, a long table is set. We sit down with the other caregivers. The team in the round of the bedridden is the last to arrive. At lunch there are not many conversations. After lunch, the teams resume work, as they only have about one hour's work left ahead of them. Maria explains to me that in that time they will not do much, they visit some houses to do some hygienic care, but nothing special: 'We don't have time. The later one's deal with the rest'. In the afternoon they don't visit António, so I had to finish my observation for that day.

The next day, when I arrived, Maria was already in the locker room. The caregivers are talking about António. In 'The Book' it says that the afternoon team found Antonio's door lock damaged. Maria explains: 'They thought that maybe someone tried to rob the house, but a neighbour come talking with the girls and says that it was him, trying to open the door. Apparently, he wondered in the garden and returned in the house...'

It is worth noting that while Maria and Ana said that António's neighbours did not want to get involved, it was the neighbour who told the caregivers what happened suggesting that that they did in fact pay some attention to him even if they preferred not to get involved in his life. In the book it's written that the caregiver had no contacts to solve the problem and that there was no locksmith available, so they tied the door lock with string. The caregivers are apprehensive about the situation. All agreed that he should be institutionalized and that trying to get out was a sign of despair and loneliness. Maria says to me: 'I hope we don't find anything worse this morning'.

Before we go to António's house, we visit a couple and at the end of the visit, the lady asks Maria if she can go to a drugstore after her work to buy her some ointment. Maria refuses, saying that she has enough ointment and it doesn't make sense to buy more now. In the van, I ask is it's normal to the care users to ask those kinds of favours to caregivers. They told me that it's quite common, but that they avoid accepting to do it:

We don't have that much time, we work eight hours but they aren't eight normal hours and they want me to go tasks for the users? I can't...if I see that is really urgent, I accept but when I know that they have children and grandchildren who can do it for them, I say no.

She takes advantage of the silence to add: 'This work is difficult. We do the best we can, and they don't always recognize it. It's a bit ungrateful'. At this point, I wait a little longer for her to continue, but she says nothing. I ask what the most unpleasant situations are

when they say that we don't make the effort. We don't have enough time...we wish that we could spend half an hour or even one hour with each one of them. But the houses are far apart, we lose a lot of time on the way and all of them need to have the same type of care. We cannot spend more time with some of them and less with others.

When we arrive at António's house, we see that the door is half-open. Maria comments that she hopes nothing has happened but António is in bed. Maria and the other caregiver<sup>7</sup> enter the bedroom:

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<sup>7</sup> Ana was not with us that day.

Maria: António, what happened?

António: I was waiting for you...

Maria: Yeah, but they said that yesterday you tried to open the door, is that true?

António: Yes, I wanted to go outside.

Maria looks at me; she doesn't know what to say. They began with the routine of hygiene care, while they explain to him, 'You know that you cannot leave the house alone...'. António answers: 'Not alone, nor accompanied, I don't leave the house!'. Silence. Caregivers don't insist on the subject, and they dress him and take him to the kitchen to have breakfast. The other caregiver calls Maria, leaving António in the kitchen. The caregiver has a knife in her hand, 'I found this on the floor, I guess that he cut the string with it'. Maria grabs the knife and goes back to the kitchen. I thought that she would say something to António about this, but she passes behind him and hides the knife in the cupboard. She looks at me and says, 'Now he doesn't know where it is'. António continues to eat passively, not paying attention to what is going on around him. After breakfast, as in the previous day and the other ones after that, Maria and the other caregiver take António to the living room. He complies with the orders without asking any questions. When we left the house, the door had not been fixed yet. The caregivers pull the door and try to open it again, but it is stuck. Maria's colleague walks around the house, quickly comes back and says there is a key to the kitchen door. They decide they'll put that information in the notebook if no one comes to fix the door. After this, we visited two more houses and returned to the institutions to the caregiver break.

During the break one caregiver complains about excessive workload, of having to do things in a hurry. Maria comments that they lost a lot of time in Antonio's house because of the door problem. At lunch, Ana, whom I join again after the break, tells me that for her it's not only physically exhausting, but also psychologically very heavy to be a caregiver. After the death of one of her brothers she began to pay more attention to the situation of the elderly. If before she tried to distance herself from what was happening, now she is more sensitive. She says that she began to realize that 'The reality of the elderly I care for will be my reality, my future'. She explains that ever since she tried to focus more on what she does, and to give the best she can: 'Loneliness kills, you know'. We can observe in this situation that the psychological pressure upon these workers is high, to the point that it is almost as if there was a disembodiment, as if they are not there. 'We get used to doing intimate care, at first it was hard, but now I do what I do what I have to do and don't really think about it'. Ana explains to me that she would like to take care of her parents in the same way that she takes care of the care users, but she thinks that she may not be able to do it. 'They don't need it now, but they will, but I can't leave my job. I don't have the money to do that, I need to work. We earn so little, if I get time off on medical leave it will go even lower...' [the financial support during medical leave is about half the base remuneration]. I ask her if it's not possible to use the same services as the one in which she works for her parents. She says she would rather not

because I know what it's like to work here. I know that as much as we like the care users, we don't have time to give people enough attention. The worst for these people is loneliness, it's way they always want us to stay longer, to do this, to do that...because they feel lonely.

In cases in which the HSS is the main carer, it's more difficult for the elderly as for the caregiver, who must turn their heart 'into stone' to continue working and go on to the next house.

During lunch time I had the opportunity to talk more calmly with Ana and Maria. Both have been working in the institution for about 15 years and neither of them have worked in any service other than HSS. Both defined their relationship with the elderly as healthy, even though at the beginning they find it a little troubling:

When we meet the elderly for the first time, in the beginning it always a bit difficult. There are people who accept more easily than others. They are bothered by our presence and us touching them, especially when they are aware. Imagine having two strange women walk in your house and start washing you? They are no longer children, but I think I have a good relationship with them all. We gain more confidence with time, we begin to know more about them, about families...it's all a matter of time and being attentive, to listen to them and they need.

Maria and Ana admitted they didn't know anything about the law that protects caregivers. Both explained what they know about labour law that refers to the regulation of their vacations, days off and payment, but they were not aware of anything else specific to their profession. I asked them if they knew they had the right to receive continuing vocational training, and if they had had access to it when they started working in the institution:

(...) hum...no...we learned from the practice...by seeing other do. Sometimes we have training, but it's got to be on our days off, and I think it's a bit unfair. We already have few breaks... [Maria]

Well, but it cannot be on work days either, right? Then, who does the job? There isn't enough staff! There are always people on medical leave or on vacation. [Ana]

Regarding working in private households, both caregivers stated that they preferred to work on the HSS teams than in the nursing home – although they didn't have this experience, but they had an opinion based on what they heard from the colleagues they met at lunchtime. For them, the worst of working on private household is getting used to the space and working in other people's houses:

At first, I always feel a little bit shy... I don't really like to go into people's home, but I got used to it, I try to pretend it's a relative's house. For me it's the easiest way to deal with it...to think he's my cousin and I'm going to visit him. [Maria]

We kind of need to forget that we are 'invading' their private space. [Ana]

For Maria, the big difference between working in the household and others work is the intimacy:

It's different because it's way more personal, more intimate. It did not happen to me, but for the colleagues who came from the factories,<sup>8</sup> this is much more impersonal, they are

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<sup>8</sup> During the crisis, a lot of factories closed, leaving a great number of women unemployed which were directed to work in care institutions, both with elderly, children or disabled.

all together, but it is not the same as being in someone's house every day. It's more familiar.

For Ana, it's normal that the care user thinks of them as a part of the family and not only as workers. Maria adds that they may not think of them as daughters but more as distant relatives, but that sometimes they can be more than daughters, as for some of the care users they are the only people they see. Both of the caregivers consider being paid for care is almost the same thing as being paid for other types of work: 'It's different because we are doing something that before was exclusive to the family. But the times change, and now the family can't help their elders, so we have to do it for them...'

For Ana, the question for some families is more that they don't want to do some of the care practices (change incontinence pads, toileting) and she thinks that it's quite sad that they need to ask stranger to ask others to fulfil these basic needs for their parents. For her, the family should keep doing care work for the elderly, since it places the individual in a situation of vulnerability and distances him/her from family relationships.

For both caregivers the best time of their days are the moments when they can establish a relationship with the elderly and talk with them. They also underline the fact that not being 'locked inside a building' [Maria] is one of the best part of working for HSS: 'But the best part is talking with the elderly and being able to see so many people...it's nice, there are always something to talk about. It's almost like we are going out (laughs). I like to hear about their life, how they spent the night...' Maria explains that sometimes the elderly makes up stories about their life but Ana says they have to pretend it's true and try to talk about things they like. Many of the care users have worked for many years in the fields, so they talk a lot about agriculture. What they find particularly difficult is to observe the degeneration of the care users and to know that some of them are alone. They are alarmed about what might happen to them between visits: '(...) the worst thing is to see them getting weaker...sometimes the changes are small, like in a week they can turn themselves in bed and in the next week they cannot. Those who can still take bath alone and suddenly they need our help completely' [Maria].

I don't like when we leave, and we know that they aren't alright...like when they are sick or in pain. When we know they stay with their family, it's alright but cases like António...we have 'our hearts in our hands', not knowing what to do but we know we cannot stay there, right? It's not our job, we don't go there for that. [Ana]

As we will also see is the case for some of the workers working in the nursing home, the relationships between employees and the administration is a little distant. He/She only resorts to the gerontologist in charge in emergency situations: 'Oh...we hardly see Dr. L... basically we just talk to her if there is a problem with the timescales, if we need a specific day off. She sometimes leaves us messages about something on a post-it' [Maria]. Without concrete guidelines on how to perform the job, caregivers aren't free to change small details, even if they don't agree with the way it is performed. In their opinion the administration lacks knowledge of the reality on the ground. Although they don't have a negative opinion of their employers, they consider that the HSS gerontologist should spend more time with them:

I think it must be someone who is always attentive and I think they should go from time to time with us in the vans, to see that the work is like. They aren't always here, they don't know the real life...they know the theory, but they don't know that sometimes we arrive in a house and the care user is very dirty and we cannot take only 15 minutes, the hygiene will take more time. [Maria]

For Maria a good care worker needs to be kind and have a lot of patience:

It has to be someone who knows what she is doing; or who is at least willing to learn. A good caregiver cannot go to work by force. You have to like what you are doing, if not, it's better go and find another job. Although I don't think that anyone can replace the family. [Maria]

Ana, for her part, considers that in some situations, is better for the elderly to be taken care of by caregiver and not their family since the fact that they are paid can serve as an incentive 'to pay attention to what we do. If my parents one-day need someone to treat them, I'll have more experience, and this will change the way I'm going to do things or how I'm going to choose someone to do it' [Ana].

When I asked about any conflict between them and the care user/family, Ana explains that some of the more complicated situations occur when the family wants to be present during the care process but don't understand what the caregivers do. She thinks that their presence makes the elder complain more, but she sees it as an attempt to get attention from their relatives. Both caregivers explain to me that they never got to the point of the family complaining to the administration and they usually solve the problem with the elderly and their relatives:

Once, a lady's husband got mad with us because his wife was complaining, because of the movement we were doing...the point is, in beds that aren't appropriate we cannot always do things the most delicate way, but I'm certain that we weren't hurting her. [Maria]

Maria had to explain to the husband that they knew how to perform their work: 'I said to him: I know your wife is in pain and believe me, I don't like to do this to her, but we don't have any other way. If you prefer, you can do it, and we'll leave'. After her intervention, the husband left the room after asking them to be gentle with the wife.

Concerning the respect that society has for caregiver, both agreed that the great majority of people respect them, as the people know the work they perform. However, they think that there are other people who don't respect their work and they feel it in small detail such as in everyday traffic:

(...) the vans are identified, right, people know that if we're are parked somewhere, it's because we are taking care of someone. Sometimes we hear people complain about that. They say that we are getting in their way and to 'clean old people' we don't need to park inside the houses. But it's not like that, if we start looking for a good parking spot and still have to walk there, we will never end the work. [Maria]

For Ana, caregivers are respected, but they are less valued than if they were doctors or nurses, even though they recognize that their work is important. She says that there are a lot of people who think

that 'they would not be able to do what we do, so when they recognize our importance and they respect us' [Ana].

In the interviews guidelines proposed by the coordinators of WP5, the last question was a fictive scenario involving a family with an elder (Tom), his daughter, and a care worker (Anna). In the scenario, Tom says that money has disappeared and Ana says she has not stolen the money. Interviewees were asked to react to situation proposed and explain what they would do. On the proposed scenario, both said that Tom's daughter should try to realize what happened and hear both sides before making any decision. Maria says that

if I were in the caregiver's place, I would have told the truth and explained what had happened, but if the daughter continued to insist or distrust me, I think I would have resigned. I will not try to force anything...I don't like to know that someone is suspicious of me.

For both, the situation would be different if Anna worked longer, because they assumed that there would be a greater relationship of trust, 'I think in a situation like that the daughter would trust more the caregiver and try to show the father that he may be wrong' [Maria]. Ana adds that a potential sense of distrust on the part of the family would be the worst and that

if I were in that caregiver's place, I would do my best to prove that I had not done anything wrong, but if they had insisted or began to watch me, I would certainly resign. There would be no way to me to work in someone's house and not being able to move something without being afraid they will think I stole something. [Ana]

In the time span between the third and seventh day of observation, there were few changes to the routine of care. António remained stable for the rest of the week, which somehow gave some peace of mind to all the caregivers. The door problem was solved on Wednesday of that week. When we arrived, the lock was sorted out. We go in, António is lying down in his bedroom with the light on. Maria comes in and asks how he feels.

António: I was waiting for you...

Maria: Really? We're late, huh?

António: I've been awake for a long time...

Maria: Well, but you know that we always arrive around this time... we cannot come sooner.

António: Well, I know, I know... but I have nothing to do either.

During hygiene care, Maria asks him who arranged the lock. António says it was his sister's husband, who visited him the day before.

Maria: Did you enjoy having sister here?

Antonio: I would prefer that she lived with me, but yes, I liked it...I always like when someone comes.

Maria: You will see that in the summer she will come here more often.

On that day, as well as during the rest of the week, the visits proceeded as observed: the caregivers helped António to get up, served him breakfast and then accompany him to the living room, leaving the door closed. The specific characteristic of the HSS implies that the visits are always the same, following the routine, with no room for improvisation. Any change in plans delays other visits, impacting on the care given to the remaining elderly. Fortunately, as I was given notice, in most of the houses that were visited, the elderly had some kind of family with them, using only HSS services for the provision of hygiene care. During those days, during breakfast and until the caregivers finished their tasks, I took the opportunity to interview António.

I began by asking him to tell me about his life. António told me that he had always lived in that village and that at the age of twelve he started working in the field, like most children at that time, helping his parents. Then as he got older he started to work on construction. He left home at 18 to work outside of the village. When he returned, he went back to live with his parents in the house where he now lives alone. His younger and only sister married shortly after that and moved out to live with her husband in another village. After his parents died, Antonio stayed alone. For a few years his physical condition remained stable enough and he didn't need support. However, as he grew older he started to lose mobility and he asked for assistance through Social Security. The Social Security referred his case to the HSS, to keep him in his home environment for as long as possible and to avoid institutionalization, and he was allocated to Santa Casa. Hiring someone to stay all day with him was not a possibility:

I never got anyone, and I think it's expensive...then on another side, I don't need a lot of care, its more with the bathing and to get dressed, and cook. I don't cook anymore. Sometimes I feel very lonely. Maybe one day I'll ask my sister if I can get someone, but I think it will be difficult.

According to him, finding 'a woman who doesn't mind caring for a man who lives alone' is difficult. In António's opinion, 'They might be afraid that I will do something, but I would never do such a thing...' Unfortunately, he was not the only elder to live alone or isolated. In most cases, these situations involve women who managed to maintain some social life. The scarcity of a family network in António's life is also reflected in the opinion he expresses about whether he would rather have his sister give him care: 'I don't know, maybe, but I don't know if she would be able to give me a bath, I think that for her it would be complicated'. The biggest problem António faces right now is that he cannot leave the house. This is a situation that he considers unfair:

I wish I could go outside more often. I don't remember the last time I went to the city...sometimes I go to see the doctor, but it's not the same thing. I guess it's the more unfair thing, not having someone to go out with me, the girls can't, they don't let them...

During the interview, António reflects a lot about his loneliness, as for him it is the worst of his day: 'I don't like the nights. The nights are bad, they pass very slowly, that's when I feel more alone...I watch a lot of television, but I quickly get bored, then I go to bed and turn on the radio, and think...' On the good parts of his day, António indicate the visits of the HSS teams: 'I like when the girls come here...I always wait for them. If they get late I get worried, I wonder if they've had an accident. Then, when I hear them opening the door I get happier... I wish they would come here more often during the day...'

For António, a good caregiver is someone with manners, who speaks well and isn't in a rush: 'Sometimes it seems that they [caregivers] don't want to be here, and they do everything in a hurry and I don't like that. I'm not a bag of potatoes...' I asked him how he manages those moments: '[I don't do anything] but I don't trust them either. When they are mean, I don't answer their questions, I'm not playful...I think they realize that I don't like their attitude...'

On another level, António says he has a great respect for the caregivers as professionals, 'it takes a very big heart to do this work and they work hard. But some people don't value their work, they must think it's nothing special, but it is, they are taking care of people! It is almost as they are mother, and being a mother is beautiful'. Since it was impossible for us to contact Antonio's relatives in order to understand why they chose home care instead of institutionalization, I decided to interview Alexandra, whose mother (Inês, 93) didn't want to participate in the study. The willingness of her daughter to share her thoughts and feelings about commodified care workers in private households was very useful.

Alexandra is 66 years old. She is a retired physician and lives about 15 minutes from her mother's house. Her mother has several children, but she is the daughter who lives closest to the mother. As Alexandra mentioned, her brothers are very involved in the mother's life and in decision making regarding what care is provided to their mother. When her father passed away in 2007, Alexandra and her brothers felt that their mother needed more support, since she was living alone: 'Of course, there were several alternatives to support her, because she was still valid, still autonomous, but knowing her as we know and respecting her opinions, we knew that it was very important to her to stay in her environment'. For Alexandra, to take a person of a certain age out of their environment can lead to significant deterioration in the individual's health condition. Alexandra and her brothers agreed that it was important for someone to be with their mother. They proposed to find two caregivers, one for daytime – 'for a few hours or more, as she would like it' – and someone for night-time, since Inês preferred to sleep in her house instead of moving to one of her children's house. In Alexandra's opinion, her mother prefers having two people taking care of her, rather than one, 'because of her character. It is easier for both, for my mother and for the caregiver. The old people have their particularities and the young ones have them also'. Inês spends the week-ends at her children's places, alternating between the six of them. The situation changed when the older woman fractured her right arm and leg. As Alexandra underlined, Inês 'lost some autonomy and after that she is never left alone; she is always with someone. If there are vacations, or days off, we take care of her'.

In the first weeks following the accident, Alexandra and her siblings (sisters) provided most of the intimate care; 'We had to wash her, help her getting dressed... and she was more comfortable with her daughters than with her daughters-in-law or other people'. Alexandra explains that the caregivers employed were not given the task of the provision of her mother's intimate care in order to preserve her modesty. At one point they resorted for a few days to the HSS, and Alexandra says the family was not pleased with the results. According to her, caregivers in the different teams didn't know how to deal with someone who was in bed with plaster. She assumes that her sensitivity to this stems from her [medical] professional experience, and that perhaps if she were someone else, she would not have paid attention. But she made a point of explaining to the caregivers how they should perform the manoeuvres to change her mother when she was bedridden.

For Alexandra' mother, the relationship with caregivers is principally about keeping her company, cooking and watching her during the night. The process of choosing caregivers was done by interviewing candidates. According to Inês her brothers were keen to ascertain:

(...) If they [potential caregivers] were trustworthy. I mean, we would 'give' them our mother, so they should be trustworthy, not only in terms of not moving in things, but in terms of treating her well, caring for her. We want her to be treated with dignity and special affection. It takes affection to treat people with some age, the candidates should have good manners, should be able to talk with her... I think it's the basics.

Alexandra says that she and her brother, also a physician, always volunteered to give some training to caregivers who were staying with their mother. According to her, 'Anyone can learn as long as they are willing'. However, she thinks that this type of training should be more consistent and be given through the National Health System in combination with Social Security:

Since I've worked as public health physician, I think that within the programmes of social action in the municipalities, it's possibly to articulate the actions performed by the various entities that service the community, whether public or private, and to give training to caregivers, both formal and informal. The health care system has resources, like nurses, physicians, nutritionists and the municipality usually employs a sociologist and a social assistant. Together we could define a programme of intervention to give training in many areas of interest for the caregivers. And related to actions in which the caregivers feel they need to learn more. We don't know what the needs of the caregivers are, what are their fears...They may be afraid of caring for someone, if they are in a situation like a cardiovascular attack. There I need to know, as a caregiver what to do and a caregiver can easily be frightened in that situation. All this can be perfectly taught in cooperation with the community. I think it's logical. I don't mean that it should be taught by private trainers, but it can be done in partnership with the community. If we think that our population is getting older, and we have a large number of elderly people, we need to think of a way to solve this question. They cannot be all institutionalized, right? We need answers from the community, I think is a question of social responsibility.

For Alexandra, the major difficult in having someone taking care of her mother and therefore in the household is related to matters around the loss of intimacy:

The main difficulty with my mother was to accept the intimacy between her and a 'stranger' and to be deprived of own intimacy. It has been difficult because the caregivers have been replaced a few times. In some stages we tried to take care of her ourselves or at least to be present. When my mother was bedridden I stayed at her house all week long. It was me who was with the other caregiver, because I knew that I could help her overcome some of her inhibitions, to have to be seen in less pleasant situations, to use the toilets, undress, take a shower... We must understand that people have their limitations. For us, we trust the person, we talk to the person, we interviewed and we decide if we like her or not...then it is a matter of following this invasion of privacy, intimacy, which my mother must accept, my mother must like the person first.

Although Alexandra doesn't know the legislation about caregivers, she thinks that there is little investment in this professional sector and believes that the legislation should be stricter on this:

I think caregivers must be trained and be selected and supervised. I think Portugal needs to take action in this area. It is a big risk in the country, with so many elderly, we cannot just think that the institution will give the good will to give training and make the caregivers capable of caring for the elderly.

Later she stated:

There is no such characteristic in our mentality as to think and plan. We are a people of 'desenrasca<sup>9</sup>', we unravel all situations and our thinking goes in that direction...there must be legislation that obliges people, institutions to have training plans, integration plans for those trainees, otherwise I don't think we will be able to provide quality care.

When asked about psychological support to caregivers, Alexandra agrees that it should be mandatory, giving, as reference, the example of her mother:

She preferred a person with her during the day and another one during the night instead of the just one during all day long, and I think that for people who take care of elders it is easier this way. Elderly people do have their tantrums, they want to rule over everything, they distrust, sometimes they have dementia problems and start to distrust the people who are with them. It's not always easy. It's not easy for the sons and daughters, and neither is it for the caregivers. I think it's useful that caregivers have psychological support to help them overcome the obstacles that arise in caring, in being a caregiver.

Finally, when presenting the hypothetical scenario of a caregiver who is accused of stealing, Alexandra expressed the following opinion:

She started working there a month ago? It can be different... We all have preconceptions and it is natural that we will be questioning her behaviour. It's natural, it's human, to question if the caregiver may or may not have moved something, but we also must recognize that our relative also may have gone through a phase, because it's difficult to accept all these problems of aging. Those kinds of confusions particularly with money are vulgar and very present. I think the only position to have is to try to devaluate that situation, give it some time and try to figure out who is right. That's what I would do, I think it's the most rational. It's not because my father says 'This thing disappeared' that I'm going to fire the caregiver or take any measure that is not well thought in relation to the person who is taking care of him.

For Alexandra and brothers, having someone taking care of their mother was clearly a necessity, so they can feel that she is safe at home. However, they assume that if she had refused this kind of assistance they would have respected her will and would have sought another solution, always trying to respect the will of their mother. But in cases like António, the will of the caregiver is not always

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<sup>9</sup> Portuguese expression that means that someone is capable to find easy solutions even in the worst situations without planning.

respected, because the familial support is not there. Neither he nor Alexandra's mother attended day care facilities. In Antonio's case, the caregivers of the HSS teams signalled several times to the institution that he should be integrated in the day centre to give him some socialization and for his own safety. In the case of Inês, the care user herself didn't feel the need to go to a day care centre since she is accompanied by a caregiver and wants to maintain some independence.

Emotionally, there is clearly a difference between the case of António and the mother of Alexandra, Inês. In this latter case, the emotional support given by the family – sons, daughters and grandsons, guarantees almost daily contact. In general, care users with close family contact seem to look at the care worker in a more practical way – most of the times related to the toileting and cleaning the house, but not as an emotional support. This removes the emotional responsibility from the caregivers which is in stark contrast to the case of António and, as will be seen below, in contrast to the situation in the nursing home. In António's case, the HSS teams are the only people who give him care (physically and emotionally), and they feel obliged to be attentive and watch his emotional state closely. Several times during the observation António verbalized how isolated he felt, affirming in the interview that he wished the caregivers would spend more time with him, although he didn't dare to tell them directly.

Both Maria and Ana experienced some difficulty in co-ordinating their work with other responsibilities. During the week of fieldwork Maria was finishing preparing for her younger daughter's wedding. She complained several times that she lacked time to deal with numerous details, while and the same time she had to take care of family members who were visiting. In Ana's opinion, sometimes, the emotional state in which she finds herself at the end of the day makes it difficult to take care of other domestic work or even to wish to spend some time with her own relatives.

#### **4.2. NURSING HOME**

In the nursing home where the fieldwork was carried out, I accompanied a team during their shift. In contrast with the HSS team, in the nursing home there are five possible shifts (see Table 3).

**TABLE 3: Number of caregivers per shift**

Hours	Nº of caregivers in the 'New Wing' [Monday to Friday]	Nº of caregivers in the 'Old Wing' [Monday to Friday]	Nº of caregivers in the 'New Wing' [Saturday and Sunday]	Nº of caregivers in the 'Old Wing' [Saturday and Sunday]
7h – 15h	2	3	2	2
8h – 16h	2	3	2	2
15h – 22h	2	3	1	2
16h – 00h	2	3	1	2
00h – 8h	2	2	2	2

It was suggested I should accompany two caregivers, Helena and Raquel, who worked various shifts, alternating between the 'New Wing' and the 'Old Wing'. 'New Wing' and 'Old Wing' is an internal division in the institution, and as the name implies, the 'New Wing' of the building was renovated a few years ago. In the Old Wing, there are about 15 persons living and in the New Wing, 10. These numbers may vary, but the institution has usually all the vacancies occupied and is known in the area for having a long waiting list. In the same place, only on the last floor, function the Day Centre, which runs from 8am and 7pm. Most of the people who use this service are absolutely independent, and during the fieldwork, there were about 10 people using a form of locomotion aid. The users of the Day Centre, take their meals at the same time as those from the Nursing Home. During the meal, they are assisted by the care workers and kitchen staff, if needed – for example, to cut food, take medicine. During the rest of the day, Day Centre users are in a different room of the users from the nursing home. In this room, they make activities with the social-cultural animators, like singing, painting, thematic decorations according to the time of the year.

On the 'New Wing' side, all the bedrooms have a private bathroom and there are fewer rooms, meaning the accommodation is more expensive. The rooms in the 'Old Wing' are cheaper and the bathrooms are shared. In both wings most of the rooms are double; one had three beds and there were few single bedrooms. Most of the people living there were widowed women and in the case of men, their disability was the main cause for their institutionalization. Since Helena and Raquel worked more on the 'New Wing', I chose to focus particularly on the care given to a couple, Susana (aged 74) and Paulo (aged 77) living on this wing. I choose them firstly because they were two of the few elders

who didn't have mental problems, though they did have some mobility issues; secondly because they were the only couple living in the nursing home.

Susana and Paulo had lived for in Luxembourg for many years as migrant workers, returning to Portugal upon their retirement. They have a house in town but since they don't have children and their formal caregiver decided to emigrate, they opted to go to live in the nursing home. In the institution, elders are left alone at various times of the day. Most of the care users are in wheelchairs, so when they are alone they are effectively immobilized when they are alone. Those who can walk, as with this couple, can be physically safe. The building, a former hospital, was adapted to minimize accidents. Access to the ground and first floors is through access ramps and to reach the second floor there is a lift used by both staff and care users. This floor is also served by stairs. All bedrooms have an emergency bell that the care user can activate in case of necessity, both night and day.

Susana and Paulo need some assistance to get in and out of bed. Susana wears incontinence pads and also needs support with washing. With that limitation they can, with some difficulty, eat and move about the care home freely. They were in this respect unique among all the care users, meaning they both enjoyed more freedom but also were more often left alone since they didn't need so much assistance. They were well able to verbally communicate with ease and covered all the costs of their institutionalization themselves.

**TABLE 4: Relationships of care (nursing home)**

<b>Context</b>	<b>Person</b>	<b>Description</b>
<b>Nursing Homes</b>	Care worker 1: Helena, aged 63	<i>Helena was an immigrant in Switzerland, where she worked as a carer for about 12 years. She returned to Portugal in 2001 and started working in Santa Casa in the summer of 2013.</i>
<b>Nursing Homes</b>	Care worker 2 – Raquel, aged 23	<i>Raquel is the youngest carer in the nursing home and was hired through the employment centre after finishing secondary school.</i>
<b>Nursing Homes</b>	Care user 1 – Susana, aged 74	<i>Susana and Paulo are a couple, and both live together at the nursing home since the summer of 2017. They decided to move to the nursing home because they don't have children, and both have been losing some mobility due to health problems.</i>
<b>Nursing Homes</b>	Care user 2 – Paulo, aged 77	
<b>Nursing Homes</b>	Family member – Fernanda, aged 59	<i>Fernanda had her father admitted to the nursing home after a cardiovascular incident that made him lose all his mobility. Since herself has been dealing with health issues and her mother couldn't take care of her father alone, the institutionalization came as the best solution.</i>

I accompanied two of the available shifts: 7am to 3pm and 3pm to 11pm. Since I already knew the nursing home care workers as they shared the lunch hour with the HSS care workers, beginning the observation was easier. When I arrived, I went directly with Helena to the locker room. As with the HSS teams, the first thing the team does when they start the shift is to read “the Book”; however, in this case the notebook is kept in the Director’s office. Helena read what the other caregivers had written and she went on to meet her colleagues who were still working (midnight to 8am). They talked for a short time. Meanwhile Raquel arrived, and Helena joined her to start their tasks.

They begin with the room where Susana and Paulo stay. Only Susana needs help washing and getting up. Paulo can take care of his own personal hygiene and is already dressed when we arrive. The caregiver leaves them alone and they get prepared for breakfast at their own pace. The caregivers are divided between the rooms and I follow them alternately. This situation illustrates one of the main problems of the caregivers: their excessive workload does not allow them to provide care as they wish. Helena explains that she would like to be more available to each care user, but there are too many people and most of them have complicated needs. There are many people bedridden or who cannot walk, a situation that demands care be executed in other ways in terms of manoeuvres used, which is easier with someone who ‘collaborates’ [Helena]. ‘Collaboration’ meaning that care users can move themselves in bed. Many of the people who are completely paralyzed are in pain and do not like to be moved. Raquel comments:

If there were more caregivers in each shift, we could work more slowly and could try not to hurt them...I mean we don’t do it on purpose but sometimes we can’t be gentler.

Both the lack of time to provide care and the lack of time outside of work to live their lives outside the institution. The lack of time is an issue frequently mentioned during the work of the caregiver:

First, we need to wake them up, although usually they are already awake. After that I go grab water and towels. The caregivers from the previous shift leave the clothes for us to dress them. Then we take off their night clothes, wash their face, hands and upper body. After that we take off their incontinence pad, wash their lower body and put on a clean pad. If they need it, we put some cream on their body and then we dress them. In the end, we sit them in a wheelchair or, if they don’t need a wheelchair, they wait in a chair in the hallway. [Helena]

One of the elders has some stuffed cats in her bed. I ask Helena if it’s common for the care user to have comforters. She explains to me that the person suffers from Alzheimer’s and that, at home, she had cats and slept with them. When she was institutionalized she was always worried about her cats so one of her sons brought her the stuffed cats to keep her company. Helena tells me that the woman treats the toys as if they are alive and that helps her to feel better and to not to ‘panic so much ...before she was always screaming, asking about the cats... she was always saying that we needed to feed them, that she should go home’.

Susana and Paulo are not waiting in the hallway but in a small room with a television. Some of the care users have been up since 7.30 and must wait until after 9h30 to have breakfast. Susana is impatient, and she approaches me to chat:

Susana: So, are you liking the ambience?

Me: It's interesting...

Susana: It's a job just like any other. Someone has to do it. That's it, we need to endure it. We arrive a certain age and this is it...

She goes away but comes back to ask the caregiver to help her use the toilet. Most of the care users prefer to use the bathroom instead of the incontinence pad which they find humiliating and unpleasant. Unfortunately, the caregivers do not have the time to accompany the elderly person each time they want to go to the bathroom.

Helena: Mrs. Susana, I can't take you to the bathroom!

Susana: But I want to go...do you know what is like to use an incontinence pad? It's not easy!

Helena: Oh dear, I know. But we don't to leave you here alone. I can't just be with you. I need to go helping the others.

Susana gives up and goes back to the room where her husband is still waiting. It is nearly 9.30 when the caregiver starts bringing the cart used on the ground floor, to the main hall where the meals are served. Those who have diabetes are taken to the centre of the main hall so that the medical assistant can monitor their glycaemia and give them insulin. The other elders go to their table or are pushed there in their wheelchairs. The breakfast is always the same: milk with or without coffee and bread that most break in little pieces to put inside the bowl with the milk. Some of them can eat alone, but others need support from caregivers. Susana and Paulo eat seated at a table with two other people. When they finish eating, they go back up to the room with the television. During their breakfast caregivers have a short coffee break. Then they go to the bedrooms to serve breakfast and give medication to those who are bedridden. They are called to move an elder from the wheelchair to a sofa:

Helena: Raquel, we need to move Mrs. S. to the sofa!

Raquel: Really? But why?

Helena: Doctor Sn [gerontologist working in the institutions and relative of Mrs. S] says o...she must think we don't have anything else to do...

Raquel explains to me that they don't think that this is fair, since they are taking more time with Mrs S than with the others, but as 'Mrs. S. is the grandmother of the doctor's husband...we need to do what she thinks is best. But it's only because she is here to treat her. It's not fair to the others.'

Between breakfast and lunch, some elders are taken to the garden by the socio-cultural worker, but this is unusual. Susana and Paulo stay in the room on the second floor. When I ask why they don't go out (since they have more freedom to move), Susana said: 'They [the socio-cultural workers] didn't say us to go also'. I asked if they would have liked to have gone with the others, and she replies: 'Sure, but the girls are always saying that it would be hard for us to walk with the walker on the pavement outside, because it is bumpy and we could fall'.

Lunch is served between 12 and 13.30, and again the caregiver helps those who cannot feed themselves. I can feel some tension between the caregivers and the kitchen staff. There is some delay in the kitchen and the caregivers must wait for a long time to serve the meals and the elders become impatient. On the other hand, they had not finished eating the main course before the dessert was served. One of the kitchen helpers gives out fruit randomly and the caregivers need to stop her, since only some people can eat solid fruit, and it is the caregivers who know who they are. Paulo asks if he can have apple puree rather than plain apple, but he is told that there isn't enough cooked apple for everyone. He mutters, 'Well, there's always enough for a certain person'. Raquel hears him and replies 'You know that people without teeth can't eat raw apple, so they are prioritized in this situation. There'll be plenty at dinner, don't worry'.

After lunch, the elders who take an afternoon nap are lined up in the hallway to be taken upstairs. There is a lot of noise, but they seem unaware of what is happening around them. Raquel goes to the bedrooms of people who are bedridden to give them their lunch while Helena goes to change incontinence pads, and help people get back into bed. Susana says that she is going to bed to help pass the time, since she doesn't have anything else to do. After their chores the caregivers return to the main hall to eat lunch. There are some elders in the main hall where there is also a television. Again, lunch is a very quiet moment.

At 2pm, the caregivers go back to the bedrooms. There is about an hour left until the end of the shift and during this time they perform quite different tasks. Raquel sees whether any care user needs to be changed and helps them getting up. Helena checks if the bathroom is clean and after that helps Raquel to get up the heavier elders and sit them in the wheelchairs. Towards the end of the shift they collect the dirty clothes and the garbage and take the trolley to the ground floor. The shift ends with them sitting at a table and Raquel recording in the notebook what happened during the shift. After that they go to locker room to get changed out of their work-clothes. When they are about to leave one care user calls Raquel and murmurs something to her, pointing to her armpit. Raquel replies, 'OK, I will do it tomorrow. Is that OK?'. Raquel explains to me that she was asking if she would shave her. She is one of the younger caregivers so some care users feel more at ease asking her to do these kinds of things, although most of the women don't really mind about being shaved or not.

On the second day, Raquel and Helena were working on the 'Old Wing' which accommodates a lot more people. On this 'side' the elders are fully bathed only once. Helena comments laughing: 'on the 'New Wing' they have a bath twice a week. I don't really know why. When I started working here that was already the rule. Maybe because they pay more they have the right to use more soap!' Helena always talks to the elders softly and playfully, and sometimes she makes them laugh. As she works, she tells me about her work: 'I have been working here for the last five years. I wish I could tell you that it's getting better each year, but it's not'. She explains that they have significantly more work but at the same time feel that they have less time to do it in, as the care users are becoming more dependent. She describes how colleagues who have worked in the institution since the beginning have told her that when the nursing house opened most of the care users were fully independent and only a minority needed full physical assistance. Now it is the other way around, meaning that the care user spends most of their time providing physical support and little emotional care. The caregivers consider this to be one of the main reasons why older people are aging more quickly. I asked her what she would like to be different:

I would like to talk more with them. I think they aren't stimulated to communicate and they know a lot of things and could teach us. There is a lady who prays several times a day, and she says beautiful prayers. It is the first time, as that didn't happen here before. We are always saying that we should ask her to write the prayers down on paper, but we don't have time for that...she says it so quickly and not always at the same moment of the day. When we notice that she is praying, we grab our phones to record her but it's usually too late. And she refuses to repeat herself. She says that God heard her the first time.

After breakfast I stay with the elderly in the main hall while they are waiting for the sociocultural worker to come to carry out activities with them. It's about 9.40 when they are left alone, some of them fall asleep and others talk to each other. One of the women working in the kitchen comes and start singing with them, but she shouts to someone in the hallway that she can only stay until 10. When she leaves, the elders keep singing religious and traditional songs alone. One of them is praying. Another is asking to go the bathroom and keeps saying, 'They left us alone...I don't see anybody'. Since nobody reacts to her commentary, I ask Susana if it is common practice for them to be left alone. She says that's it's like this almost every day, which is why Paulo and she spend most of their time in the room upstairs. For her, 'Being here or not is kind of the same thing. They say that we will do some activity but it's interesting enough to be worth the wait'. Helena, Raque and the other caregivers are all upstairs helping those who are bedridden, so they can't attend to the people in the main hall. At 11am a sociocultural worker arrives with some books in her hand. She asks if I want to participate in the activity, and when I agree she hands me a book of children's stories. I am asked to open it at 'Snow White' and to read it out loud, while she intervenes to explain the story. I start reading and the elder near me looks at the pictures on the book. From time to time, the sociocultural worker stops me and explains, loudly, what is happening in the story and asks the elders question. Although most of those present can talk, they barely answer her and look very bored. When we finish, she says to the group, 'Now let's pray. Who can lend me a chaplet<sup>10</sup>?' As they prepare themselves, she looks at me and comments 'They really like to pray'. Some of the caregivers are passing by the main hall and one of them comments that there is someone who is sitting alone in a corner. The sociocultural worker says that it's job of the 'room girls' to put the elders in a circle, to which Helena responds, 'Well, the 'room girls' can't do everything', but nevertheless she brings the person closer to the group. They are still praying when the care users from the on-site day care centre arrive to eat lunch. Some of them stop near the group and they also start praying. When they finish, they get up or are taken to the lunch tables. The food is very similar to the day before.

After lunch, the caregivers perform the same tasks as usual before their lunch break. They sit around a table after the meal to have a coffee and talk about the summer holidays. They caregivers are worried: they say that the number of people on sick leave plus those who are on holiday during June, July and August, means those months are going to be 'like hell' due to lack of staff. And they make small criticisms: 'Instead of hiring more people as caregivers, they take them out of that service to put them working on other services [laundry]'. For caregivers in this institution – both in the HSS and the nursing home – the most important issue is excess workload due to staff shortages. This means that the gaps between days off are becoming longer, leading to increasing physical and psychological exhaustion. Combined with the fact that they earn only minimum wage, this leads to feelings of

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<sup>10</sup> String with beads used by Catholics during prayers.

frustration, and caregivers' expressed a sense that their work is not recognized and respected. They see one of the problems is the lack of organization among their supervisors: 'They don't care. They simply don't care' [Helena]. After lunch, when I sit with Mrs. Susana and Mr. Paulo, they explain that they can feel that the caregivers are sometimes stressed out, but, 'They do the best they can' [Paulo].

The days in the nursing home have, in theory at least, a very strict routine. For Helena, the routine means not only that every caregiver knows what she needs to do but also gives some structure to the life of the care user: 'They know each day what we are going to do, at what time. And this gives them a sense of normality. I think that can make them feel more at home'. From my observations, the problems between caregivers and care users tended to be the same each day, repeated in a cycle and resolved without the intervention of members of the administration or the care users' family members. For example, Raquel tell me that elderly who can walk, tend to construct some routine parallel to the tasks that the caregivers need to execute:

Like, Mr. Paulo, he knows that we arrive at their bedroom at 7 a.m. He gets up, goes to the bathroom and gets dressed. After that he and his wife most of the time wait in the television room for us to call them to go eat breakfast; after that they prefer to be alone, so they come back to the living room and when it's almost lunch time, he comes to find us to get his beer. Every day is the same thing, it's almost timed. When they don't perform this routine, something is wrong.

Susana and Paulo are a very particular case as they have each other and live as couple in the nursing home. Although they are a little more independent they also seem more emotionally dependent. From time to time, Susana goes to the caregiver to enjoy some conversation. She will sometimes ask them if they need anything, even though her physical limitations mean that it's unlikely that in practice she could help the caregiver to perform any task. The two of them also sometimes request if someone can accompany them outside, or buy them some sweets, requests that were always denied, since the caregivers are not permitted to leave the institution with the care user other than for health reasons. Raquel and Helena find the couple's situation hard to deal with because they don't want to hurt their feelings. They try to be as considerate as possible but the lack of time to provide care to everyone puts them 'Between the wall and the sword' [Raquel].

The caregivers are usually alone with the care users, granting them an autonomy that has positive elements but also raises some tricky issues. For example, at weekends neither the gerontologist nor the social assistant (who are the people responsible for controlling and organizing the work and for resolving conflicts) are present at the institution, care workers are alone with the care users. On Saturday, when Raquel and Helena started their shifts they were informed that they were missing a staff member because she had to accompany an elder, who had hurt his leg, to the hospital. The social assistant, who needs to be informed when such accidents happen, did not answer the phone. Helena comments: 'It's always like this. They don't answer our calls, even though they say we always must call when something like this happens. We are left completely alone'. Raquel adds: 'No one shows up here. We get mad sometimes... not only so we have to do our work but we also have to do the work of others'.

During the weekend there are fewer caregivers working per shift. For the 3pm shift there is only one caregiver working on the 'New Wing' and two on the 'Old Wing'. The weekends can be calmer

than week days because the day centre users are not present, but between 4 and 6.30pm difficult issues can arise because this is the visiting time. This can be stressful for the caregivers, who must respond to relatives' questions about their parents without the support of managers or professionals. This can cause tensions and leave the caregivers unprotected. For example, while I was there one of the daughters of the woman who had the stuffed cats came to ask why her mother was immobilized on a sofa with a sheet preventing her from walking. A discussion took place in the hallway, the daughter explaining that she was dismayed to find her mother immobilised in this way, and the caregivers recognising that, while this was not a permanent solution, her mother's difficulties with walking mean she has to be restrained for her own safety. The daughter says that she doesn't understand why her mother doesn't have anyone to keep her company, and Helena responds that they don't have one person per elder and they have to leave them alone sometimes. The daughter is sceptical about her mother having problems walking, and another caregiver explains that this is outside their responsibility and that she needs to speak to the nurse on Monday so that he can explain her mother's health situation.

After she leaves Helena explains to me that she knows that the best would be for her to have somebody always with her but, 'If they want that they should hire someone to be with her at home. I bet she would be happier...but here we can't be looking for her all the time'. In Helena's opinion, most of the time relatives seem not to understand that their parents are unlikely to get better when they move into a nursing home. Being out of their environment makes them lose their sense of belonging, of familiarity, which accelerates aging. They also don't understand why their relatives sometimes don't want to talk to them. The spouse of one of the people confined to bed is a regular Sunday afternoon visitor and asks Raquel if she can give him his snack. Her husband closes his mouth and doesn't even open his eyes, refusing to talk. When she leaves, defeated, Raquel comments that this kind of situation is quite common. In situations when the care users are more aware of their surroundings, they pretend to be sleeping so they don't have to talk to their relatives: 'I guess they are mad at them. They must feel that they were abandoned and it's a way of them showing that they are upset'. After visiting time ends, the nursing home resumes its usual routine, with little or no alteration to the plans of the caregivers.

During my interview with Susana and Paulo, they explained to me they lived in Luxembourg for about forty years and have no children. They chose to come back to Portugal for their retirement. At first, they returned to their own home, but about two years ago they started having mobility problems due to rheumatism [according to them] and so they hired a caregiver. However, she decided to emigrate, leaving them alone. Their house has a lot of stairs and they didn't feel safe living alone and walking with walkers, so they decided to enter the institution together, 'while we were still able to walk and be a little bit independent'. Paulo explained that anyway having someone taking care of them at home wasn't a solution, since the main problem was that the house was not suitable for them to live in for fear of an accident.

For Paulo, their situation cannot be considered as unfair, since it was their decision to enter the nursing home.

(...) there are many elders who are left here by their children but for us it's not the case. We came here of our own free will. But I guess that it could be better: we could have more attention, more freedom. Sometimes we would like to go and take a walk in the city, but

nobody can come with us. We are stuck here all day long, going down to eat, coming up to watch television, going down to eat again and going up to sleep. It's the same every day.

For Susana, the worst aspect of her situation is that she has to use an incontinence pad. She would like to be able to use the bathroom when she wants and not be dependent for that on the caregiver. Indeed, this was a common issue for care users, who prefer to be able to take care of their personal hygiene on their own. Several elderly observed that to be dependent on the availability of the caregivers or constrained by the routines of the institutions (remember that in the 'Old Wing' the care users are fully bathed once a week and in the 'New Wing' two times a week) is not easy.

When asked about the best and worst aspects of their day, Susana says that the time after lunch is the worst, since it's one of the moments the caregiver is busiest:

(...) for me worst is after lunch, when we are alone in the little living room. There's not usually anyone else there... We can walk, so we go wherever we want. Sometimes we take a nap, but sometimes I don't want to sleep, so I stay here. People who are in wheelchairs can't go where they want, and 'the girls' don't take them here, so we are alone most of the time.

She explains that sometimes she likes to be alone with her husband, but she would like to talk with others. Nonetheless, she prefers not to stay in the main hall with the other care users because 'I don't like when there is a lot of noise, and there are so many people complaining. It's not easy: last night a man spent the whole night screaming...I couldn't sleep'. Undoubtedly the best times of her day are when somebody has the time to talk with her: 'I like to talk with the girls. They are nice...I like Helena a lot. She works hard but she is always nice to us'. For Paulo, the best part of the day is his lunchtime beer: [laughing] 'It's a 'sweet' I have every day. The girls keep the bottles in the fridge and every day before lunch they give me one. I can't drink much, because of the uric acid'.

For the couple, the characteristics of a good care worker are the same as those identified by António: 'They have to be kind and patient' [Paulo]. Susana added that they also need to be 'organized and friendly with each other... It's terrible when we feel that they don't like to work with each other'. For Susana, team spirit is important in the sense that when they are in teams that they don't like the caregivers are more 'grumpy' and in contrast when there are teams with a good spirit, 'the day goes better, and we see that they are happy'. The skills needed for good care work are practical skills like knowing how to perform intimate care and monitor medication. Paulo adds that he thinks they should have some professional training. Susana points out that she has heard them (the caregivers) talk about 'courses' but she thinks that the first training they have is with each other and they learn with practice. She agrees that, it would be better if they had training first so the new caregivers don't disrupt the more experienced care workers with their training needs.

In the couple's opinion, the caregiver is a part of their family rather than worker, even though they (Susana and Paulo) don't live at home. For Paulo, the fact is that, 'We don't have anybody but them and the people who we see every day are the other elders and the girls. They are our family'. Susana agrees, and, unlike Paulo, she is able to give an example of a disagreement she had with the caregivers, because of asking constantly to go to the bathroom: 'They were always saying that if I can't go by myself then I had to wait'. She said that she eventually got used to waiting: 'I know it's not their

fault. They do what they are told to do. I try not to ask them too often. When they say they going to take care of me I wait, but sometimes they forget and start doing other things.'

When asked about what they most like and dislike, both said that not being alone is very important:

I like having always people around us, so we don't feel so lonely. But it's also bad, because we are never really quiet. There is always something happening, someone walking in the hallway and I like calm, but we can have everything. [Susana]

I like the conviviality, being with other people, during meal times. It's nice. [Paulo]

Susana said that in some ways she feels at home in the institution although it isn't the same, but for her the caregivers do their best to give them a little sense of home: 'They clean our bedroom every day, leaving it nice and tidy, and they let us put some personal decoration, and that helps.' She later showed me bedspreads and pillows they had brought with them when they entered the nursing home to 'make the bed more comfortable'. They also displayed some family photographs and photos of the time they lived in Luxembourg. Susana comments that she knows some elders put religious figures on their bedside table but she is not religious enough to need that in her bedroom. Paulo adds w that they also had asked for a television in their bedroom: 'We eat at 7.30 and when is time to go to bed, I'm not sleepy. With the television in our room we can watch it if we want. We watch the news and my wife enjoys watching soap operas.'

Paulo thought that caregivers should receive more for their work: '(...) maybe not as much as a physician, but I don't know, maybe 800 or 900 euros... they work a lot. This is not easy, they work a lot and they hear a lot of ugly things from some care users who aren't happy and it's not their fault'. He adds:

I don't think it's a fair remuneration for their work. Do they receive more for working during week-ends? [I explained that they do not] ... Well, that's wrong, because nobody likes to work on week-ends, but we need to have somebody with us here. At the week-ends nobody else is here, not even the sociocultural animator. If the girls have to work on the week-end, at least they should be compensated.

They said that some caregivers don't like working in the institution and are only there because they have no other choice: 'They are grumpy, are harsh with us... when we try to make some conversation they ignore us'. In contrast, caregivers who like their work are 'kinder. They have patience, are always smiling, even at bad moments. I think most of them like working here, or at least if they don't like they don't show it [laughs].'

Raquel and Helena seem to be two very different kind of caregivers. They began by explaining why they started working as caregivers: for Raquel it was a matter of chance, since she needed a job after finishing compulsory schooling. Helena had a longer history in working in the sector. She had worked as a caregiver for 12 years in Switzerland, then as a caregiver in a private household for five years and only after that did she start working at the nursing home. They both said that they have a good relationship with the people they care for, although Raquel said that 'I try not to get too attached to them. I'm afraid of being too emotional because I know that someday they will die and I don't want

to suffer too much with that'. Helena said her relationships with care users are based mainly on empathy as she takes care of them the way she would like to be cared for. She makes efforts with little details: 'If I have time I like to make a fruit puree so people who can't chew can also eat some fruit. They like it, and it's a simple thing'. In contrast to Raquel, she feels that she is too sensitive to not engage emotionally and only provide physical care: 'I like to be kind to them and play with them, talk, give them some incentive so they don't stop doing things like walking, or eating.'

Neither had a strong opinion regarding care law and policy. They were aware of their rights as workers and the protection they have under the Portuguese Employment Code. During the observation I noticed that their main issue was their salary and the fact that they are alone during the week-ends. This latter may seem irrelevant in terms of law and policies, but for them, being alone with the care user is a problem, especially in the moments when relatives are visiting and asking questions.

For Raquel the main difference between being paid to provide care and being paid to provide other services is the fact that they are responsible for the lives of elderly people. Helena refers to the moral obligation 'To care for them, to be aware of their necessity'. She recalls the times she worked in a private household, where when the elder died, one of his grandsons was living in Brazil. He couldn't come to the funeral and, 'when he came on vacation and met me again, he hugged me and thank me for taking care of her grandfather. This kind of thing doesn't have a prize. Even if the work is hard, the emotional side makes it worthwhile'.

For Raquel the best aspect of her day was helping care users to eat because it's 'like helping a toddler', and the worst time was after lunch, when they needed to check if people are clean and change them, and take them to their rooms upstairs and back down to the main hall. 'At that time of the day I'm already a little bit tired and it's hard'. For Helena, the best time is working on the afternoon shift and putting people into bed: 'It's very sweet. Some of them have their own routine and always ask for hugs. Some of them say prayers'. In contrast to Raquel, Helena finds the worst time to be lunchtime because there are so many people in the main hall. She thinks that having people from both the nursing home care users and the day care centre means that there are too many people to deal with.

In common with the HSS team, the caregivers did not think that the institutional administration was particularly involved with their work. They issue individual guidelines if a care user needs a particular kind of care or if relatives have a specific demand. For Raquel and Helena, a good employer is someone who is 'fair' with their employees and respects them and hears their demands. Helena added that she doesn't think their employers are bad, but she considers that they give some employees preferential treatment and are unfair when distributing the days offs each month. She says that she has been working on every public holiday while the administration permits some of her colleagues to never work on those days. Although she considers this situation unfair for her and others, she adds that, 'I don't like to ask for favours. I think that if they are the bosses, they need to know what is the right thing to do. It's not me who's going to teach them what is fair or not. I'm here to work, not to beg'.

The characteristics of a good care worker are considered to be the same for both the HSS teams and the care users: a caregiver needs to be kind, gentle and patient. They think that a good paid care worker will like their job more than an unpaid family member who isn't providing care by choice but

because they have to. For Helena, if the family member isn't comfortable with what they are doing it can be worse for the dependent than being cared for by a 'stranger' (i.e. a paid care worker). They also share the opinion that they are respected in society, although for Helena people who don't work in care work can be more respectful of their work than those working in the same space:

There are people who work here in other services who don't respect us. They don't see that the 'helpers' are those who work more and have more tasks to do, and they don't respect our effort and dedication. Like the women working in the laundry service, they think it's our responsibility to put the clothes on to wash at night...but they don't see that we don't have the time to do that! Our work is given little appreciation. Sometimes we would like to hear a word of encouragement but no, instead they are always rude to us and giving us chores that aren't related to care.

As far as they know caregivers have the same rights as standard workers. Helena adds that based on what she knows from other people, caregivers in private household sometimes don't have the same rights as standard workers when it comes to holidays, days off and social security. She thinks that the situation of those workers isn't fair and they put themselves at risk in terms of their future, since they will not have a good pension if they don't pay taxes. She also recognizes that working for an institution is better in that sense because they are more regulated and can't enter into these kinds of arrangements with their employee. For her, the fact that the institution cannot afford to hire more care workers makes life difficult for all of them since they have to work for longer periods between their days off and most of them are showing signs of exhaustion.

Raquel recognizes that there is an emotional bond between workers and care users, but she doesn't think that they can be considered part of the family. Helena disagrees:

Yes, sure. During the years I was working in that house, I was a member of the family, but I think that's depends on the families. Some are more like in the "olden days" and they think of the caregiver as domestic workers and they don't include them as a part of the family. Here in the nursing home, after a certain time, they start considering us a part of their family because most of them don't have visitors. It's not unusual that they begin to think that we are their daughters, sisters...or they begin to call us by the name of the person they miss the most.

None of the care workers who participated in the research belong to a trade union. Raquel said that she didn't have the time to get involved in politics. For Helena, it was to do with 'not having patience'. She did not see any harm in the unionisation, but she is not convinced they are able to do anything to protect workers' rights:

Here in the nursing home some workers are part of the union, but they were only able to get us more days off but nothing more. And the situation didn't change that much. The people who can make the big changes are not the people who run this institution, but rather the people who are ruling the country. The nursing home will not get richer overnight so they cannot increase our wages, but if the government doesn't raise the minimum wage, they will also not give the extra money to the institution and we will continue to receive a pittance.

Giving an example of disagreement with their employer, Helena recalls that one day, one of the directors changed her timetable without her consent:

She changed my day-off, which was also my daughter's birthday, without asking me. I didn't ask for the day off because when the timetable was given to us, I was not working on that day so I didn't say anything. The day before I casually went to the director's office and saw that my timetable had changed. I was furious. When she arrived I went to talk to her and I told her that she couldn't do this kind of thing to people. If she needed to change the timetable of the employees she should tell them, because we don't have any obligation of going to her office every day to check if she has been playing with our days. And I told her that if she did anything like that again I wouldn't come to work. She didn't answer me but now when she needs to change something she always calls me first.

She didn't recall having problems with elders, although she admits that sometimes they can be stubborn. Raquel and Helena stated that their disagreement with care users are resolved through dialogue, and most of the time, they arrive at an understanding without needing external interventions. Helena added:

We need to understand that psychologically, for them, living in a nursing home it's not easy. They are always here, most of them were used to being all day outside, working and they miss being free to do and go where they want.

Helena was sure that she would prefer working in people's private homes instead of an institutional setting:

It's a different kind of atmosphere. It's more calm, we have more tranquillity and we can be more focussed on the individual. Here, we are always running everywhere. It's complicated to deal with so many people and we lose the human side that I think is the thing I most like about this work.

Given that it is often considered that institutionalization isn't a just solution for the challenges of the ageing population, the question arises: why do people decide to institutionalize their parents? For most of them it is a matter of giving them the comfort they need. Fátima, the daughter of a care user of the nursing home, chose to institutionalize her father after complications following a hernia in the summer of 2013. In a matter of days, he went from being perfectly healthy to partially paralysed and unable to talk. Fatima says that the problem of the kind of care that should be provided for her father started at the hospital. When her father left intensive care and went back to the infirmary, a physician recommended:

'Take him out of here or we will catch another bacterium!' She was a little bit rude and I told her that I wasn't taking my father home that day. My house didn't have the facilities to cope with him in the state he was, in a wheelchair. I have a mother who is 79 years old, a disabled brother and a husband who teaches in Santa Maria da Feira, I couldn't take care of my father alone.

She decided to seek help at the Social Security office, where she was asked to put him on a waiting list for continuous care services. In September they were told that there was a vacancy in a unit. For

Fátima, that institution was a guarantee that care would be provided to her father. Between October and November his health deteriorated and although he had shown some improvements with the help of physiotherapy, they couldn't stabilize his medication and he was agitated and his diabetes was aggravated. Sometimes he didn't recognize his family. He ended up staying in the unit for one year, not only because his health condition didn't improve enough for him to be transferred to another type of care service, but also because Fatima had breast cancer which led to the Social Security asking for her father to be able to stay longer. However, Fátima is aware that she only had this opportunity because 'I knew how to move inside the system, to whom I needed to ask for help', and she felt that 'morally I was taking the place from someone whose health could still improve'. She knew that she couldn't take her father home, even after making some alterations in the bathroom for him to be able to be bathed, and the problems were compounded by the mental instability of her father who became very disturbed. A year later, she decided to put him on the waiting list of the nursing homes near home. The first one with a vacancy was the institution where we conducted the ethnography: 'That vacancy appeared, and Dr.G. called me, it was God who was on my side'. Sadly, her father passed away after a year.

Fátima explains that the care provided in the two institutions are quite different: 'In the continuous care unit there is a physician present twenty-four hours a day. They have a different attitude'. But for her, nursing homes are important and that need more support from the government and care workers deserve considerable respect: 'the work of those people [the care workers] must be praised', although she recognizes that, as in other jobs, there are 'bad and good workers (...). To work there you need to have a big heart, you can't be just waiting for your salary. Those who are there just for the money don't do a good job.'

Affection is the main characterisation of a good caregiver. For her,

the emotional part is important. They need affection, they need it. Independently of their limitations, of them not being here mentally and being psychologically down, they are human beings. They need to be well treated and the person who is caring for them needs to think: "This person was like me and now they are limited, I will do my best". They need to have a heart and be the right kind of person. If they are there just for money, no. They aren't assembling parts in a factory.

When asked about the respect society gives to the care workers, she thinks that they are indeed respected. When they are not respected it can be because of the care workers' attitude:

I think that they sometimes have some negative attitudes, but I think that it's due to the way the [elder] families treat them. They don't respect them; they don't know their work. They think that because they pay 900 or 1000 euros, the care workers have an obligation to...they have the obligation, but it's also hard for them. That work is a great effort for them [caregivers], getting them up, changing them, washing them, it's complicated. But there are people who are so selfish: "Oh they are there for that, and I'm paying them", but it's not that like that. They are also made of flesh and bones. There are a lot of people who don't value, and the caregivers create defences and they confront everything. Even when they are criticized, they do their work the same way, they give all the love they can give, they treat them well and have a good relationship with the care users. They also are

under the pressure of the administration. They say to them that they can only be with each person for 15 minutes, but it can't be like that. With one person they might spend 15 minutes and with another 45 minutes. It's all relative, it depends on their relationship with the elder. This causes a bad feeling and it's related with those who are higher in the hierarchy. Most of them [care workers] have a bad reputation, but not for me. Some people don't give it value. I do.

During the time her father was in the nursing home, she recalls only having one big disagreement with the care workers. One day, when she visited her father, she found that some clothes were missing – her father's name had been embroidered on them. When she asked where the clothes could be the caregiver said it was possible that the clothes could have been mixed up with the clothes belonging to one of the HSS care users. Fátima said that she didn't like the attitude but sorted the problem out directly with the caregivers, choosing not to complain to the administration. She ended the interview by remembering that it's our moral duty to take care of our elders or at least to make sure that they have the best care possible. It might mean placing them in a nursing home but this solution should be the last one:

My father could never have stayed with us at home, but there are families for whom their parents are a nuisance. They forget that when we were babies they took care of us, tomorrow they will also be 'babies' and we need to take care of them. But I hope I can keep my mother at home with us. If I can I want to give that comfort. I will try to hire someone to provide care at home... But nursing homes are necessary, and we will need them more in the future.

All the interviewees felt that the characteristics of a good caregiver were related to the emotional aspects of care, but the emotional demands placed upon the care workers are higher in the context of the nursing home. There were several moments when Susana and Paulo wanted more attention, asking for the care workers to stay with them a little longer or to not be in such a rush. Or the elder in a wheelchair who, each time someone walked past her, would reach out her hand to give a hand shake. She would even pull the other person, so she could receive a hug. The care workers explained that she does that to anyone, even people she didn't know, which can be seen as an example of the emotional demands of institutionalized people. I certainly experienced that during fieldwork, when care users begged for attention, asking questions about why I was there and telling me all about their life without me having to ask anything.

The care workers usually worked forty hours a week. However, because of the shortage of care workers some of the weeks could go up to 56 hours including cover work. When this happens, the week after the employee has days off in lieu. However, this caused workers' considerable problems because of having to co-ordinate with other unpaid caring responsibilities. More generally, their levels of physical and emotional exhaustion left them with limited capacity to provide care for their own families. Helena and Raquel also claimed that there were many care workers with depression and taking medication due to the pressures of work-life balance.

### **4.3. REFLECTIONS AND COMPARISONS**

Care work is a career that is not suitable for everyone, and as we've seen, done mostly by women. As Helena explained to us during the week, that in the institution men aren't employed as care workers. In her opinion:

Women are abler...and most of the users don't like men. We had a man working here, once, but he didn't stay for very long. Women care users refused to be washed by him and I think it's natural. They don't even get naked in front of their sons, imagine in front of a stranger.

The care workers with whom we worked on this research, told us and demonstrated through their behaviour that, although they think care work is hard, their professional life gives them pleasure in their everyday lives. As Helena explained, emotional bonding with the care users is one of the main things that keep them going throughout their work. Knowing that they are needed and useful to someone gives them a sense of achievement. However, Raquel, who was the younger care worker, stated that although in her everyday life she enjoyed working as care worker, from time to time she thought of having a life more similar to people of her age, studying or having a less physically exhausting job, like working in a restaurant. She couldn't say if her life was as she would like it to be, she didn't think it was a bad life, since it was her choice. For the older workers, their main issue with the gap between their life and the 'life they want' was the lack of time to be with their own families. Ana for example mentioned how conflicted she would feel if one day her parents needed support and she was unable to provide it herself and had to hire someone because she was too busy working as care worker of others.

One of the biggest problems for the care workers who participated in this research is the lack of knowledge about law and policies about their work. In Portugal legislation on care is not particularly consistent and, from what we could observe, the employers did their best to comply with the law, but the care workers did not seem to know to whom they could direct their demands. Care work seems to be embedded in a double line of thought: on the one hand they are highly respected for the work they do, particularly because of its emotional aspects. Physical provision is also well valued but the investment is still poor as is evident from the lack of workers' training and their low income. The demands for justice made by care workers were limited and vague, and they accepted the lack of public recognition of their work. The networks created by the IPSS to provide care somehow forget about the link of the chain that are the care workers.

In their 'justice claim' the word that appears in the care worker discourse is the 'right to', since they know what rights and duties they have, but the limited participation by members of the administration (social assistant, gerontologist and others) in the active life of the institution make it difficult for the care workers to have the opportunity to make justice claims in response to their situations. In some moments, during pauses and when they were alone, the care workers talked about 'going to tell what is going on between the workers [regarding issues with the laundry staff and others] the administration' but, as far as we know, this never happened. The care workers complain not only about their low income, but also about the amount of work they have. However, they mainly complain to each other which reflects on the limited capacity they have to resolve the issues they face. It reflects a loss of trust in the institutional capacity of the state to guarantee redistributive justice.

In terms of in their relationships with the care users, there were multiple demands made of them, particularly those working in the mobile units. Taking the situation of António for example, anything he needed was filtered through the care workers and only later passed on to members of his family, or in cases where the care workers couldn't resolve the problem, as with what happened when he broke the door lock. Most of the time care workers do their best to fulfil the needs of the users but nonetheless, they sometimes leave the user unsatisfied with their work, particularly when care users demand they spend more time with them. Ana recalls also the demands of the users for her to buy things for them outside their working hours: 'If it's something I can get when I go shopping for groceries for me, I try to make an effort, but it's something else, I have to say no'. For her, denying these requests was also a matter of not transforming those favours into a habit that could become a burden for other colleagues. Indeed, it is not among their duties to provide that kind of help – although in the guidelines of the home support service (see above) it's stated that they can accompany care users outside to grocery shopping, going to the doctor or other appointments. In the case of the institution where we worked, this support was not available.

Equality, principally equality of opportunities and treatments regarding the users is very important for the care workers. For them, the fact that some users have a family, a nice house, and somebody to care for them between their visits is unfair to those who lack these supports. This gap between the opportunities available to users leaves the workers restless, and they find the loneliness in which some users live distressing, making them feel responsible for those people.

Conflicts about time feature significantly in the working lives of care workers. In both home support service and the nursing home, the workers refer to the lack of time they have to provide care, having to rush between users and getting nervous when, for any reason, they need to spent more time with one of the elders. In other research with commodified care workers this question also arises: "the 'lack of time' to execute the task and the lack of recourses available were referred as obstacles to the providing of care" (Barbosa et al, 2011). Another component of conflicts regarding time is related to the general overload of work and the psychological stress this causes. Symptoms of stress and burn-out are well known in this profession and the fact that most of the caregivers working in the institution had some kind of symptom related to anxiety, stress or depression is a result of this. Although, in this context, they don't work overtime, the caregivers found it difficult to go home and be fully relaxed, as the problems of the care users go home with them. To overcome this issue, the care workers presented two solutions, one was to limit the time between the days off, since there are months in which they have a full week of work and then the days off all together; the second solution, to which the previous one is closely related, is to increase the number of care workers allowing more time available to each user and also more rotation between the workers in each team so they can have more rest. Unfortunately, in the case of care provided by IPSS, this can only happen if there is more investment from the state or private investors. In the case of the IPSS, as *Santa Casa da Misericórdia*, a part of their budget comes from donations from the church and other individuals, since it is an institution with a strong religious tradition. Thus, it is difficult for the Administration to increase the available budget to hire more workers.

As explained in the introduction, it is recognized that it is better for the elderly to stay in their environment. However, Portuguese government have been reluctant to create the conditions for the families to be able to take care of their relatives. The document presented in 2017 (Petition nº191/XIII/2ª) proposes more support to the informal caregivers but also to reinforce and diversify the

formal structures that can provide care and substitute for the informal caregivers so they can rest. This suggests that the IPSS needs more financial support to hire more care workers, especially in the Home Support Services teams. If informal caregivers could guarantee that they would not be dismissed from their work for taking time off when they need it to take care of a relative, and if they could also have access if necessary to financial support the likelihood is that fewer families would need to seek help from commodified care work freeing up places for people like António or Susana and Paulo who don't have a family network to support their physical and emotional needs.

As São José (2011) presents, “intergenerational family solidarity is not in crisis” what is in crisis is the welfare state and, in the case of Portugal, its coalition with the welfare society that functioned for a long period of time but has been deteriorating since the economic crisis. On one side, there are families who can't afford overpriced commodified care (Alexandra explained during her interview that there are care workers asking for high incomes for live-out care arrangements) who have to take their relatives back home. When they don't have the capacity to provide care for them, they have to leave them alone which increases ageing and loneliness. On the other side we have institutions accommodating people with complex needs meaning they are not able to give their workers the decent working conditions, inducing work overload and burn-out. As surveys (Alber & Kohler, 2004; Daatland & Herlofson, 2003) conducted in Europe show, in the Southern European countries the preference is for family care arrangements, with families preferring domiciliary care or day centres to maintain the elders at home : “putting the elder person in a nursing home is equivalent to giving them an earlier death” (São José, 2011: 4). Thus it would seem sensible that investment in home care should increase. However, although in recent years the number of services available in this sector have been increasing, there is still limited access for most families with low incomes and the financial help provided by social security is not enough to offer unconditional help to all families to pay for the services of a commodified care worker.

A type of care more personalized seems to be one way to help dependent people achieve the life they want, instead of a 'normative' type of care – that is, equal for all the person. In the case of António, home care is the best possible response to his basic needs (washing, cleaning the house, eating) but the relational component of care fails to be provided. António is alone almost all day, and yearns for company. It seems that for the social security and the institutions, his case is not considered urgent enough for another solution to be found, but for the care workers – who are undoubtedly closer to him – his needs are not properly met and his mental health is deteriorating faster than it would be if he were fully include in the community. If we take as reference Sen's capability approach (Sen, 1989), António isn't using his full capabilities to achieve the best quality of life; and these capabilities have been taking out of him due to his financial situation and health. It isn't hard to see the injustice in this situation, especially when we compare it to cases of other elders to whom home care is provided. Inês, in contrast to António, is still able to have a say in how her life should be, and is able to decide what's is more fair for her situation. For Susana and Paulo, although living in an institution wasn't their ideal life they preferred it to living at home alone for fear of a potential accident. For Susana, the situation was a little more complicated since for her, losing her independence regarding her body (that is, being able to use the toilet alone, take a bath when she wants and not when it is scheduled for her to do it) was something difficult to accept. Also, as in the case of António, the lack of time of the care workers to provide more than physical assistance was difficult to deal with. Susana and Paulo benefited from living in an institutional setting with more persons in the same situation and from the fact that they

are able to wander as they want and that they could communicate with ease. This was a way for them to feel more free, enhanced by to the institution's policy of letting users decorate their bedrooms as they want. In all these cases, what one sees is a 'deficit' of care, translated into the reduced time available to be spent with each care user.

One of the things that appears in both the care arrangements (home care and institutional) is the infantilization of the elderly. The care workers, when alone with the users tended to talk to them as if they were talking with a child. In one way this is a form of showing affection, but several times the caregivers commented on 'how they [the elder] look like children when they are in a situation of dependence' [comments from care workers from the HSS team]. Even though not deliberate, this attitude can function as a form of social exclusion of the elders, who have "limited participation, not having access to all social rights, material deprivation and lack of normative integration" (Anderson, Hartman & Knijn, 2018). The basis of this social exclusion is individual's categorization and age, along with gender, race, religion, ethnicity. Treating an elderly person as a child is a way of taking away their responsibilities. This can include social responsibilities like voting. Helena recalls that in the last election, none of the care users living in the institution voted and Ana confirmed that the same was true for home care users who lived alone, who were not even asked if they wanted to vote. If this is the case for other care users in the country, there is a risk that a significant portion of the population is not politically participating and represented.

Disability has further implications in the life of care users and caregivers, with an emotional weight when associated with ageing. In the case of the participants of this research, the two conditions go hand in hand and are connected. 'Social alienation is a common experience at the beginning of the 21<sup>st</sup> century (...) the fear of being alone is terrifying to those who are lonely' (Rokach *et al*, 2006: 682). As we have seen, both care users of the HSS and of the nursing home felt profoundly lonely and bored. Humans are highly social beings and cannot be dissociated from life in community and connections. Also, intellectual stimulation is needed to maintain a healthy life, and this can be achieved by socialization on a daily basis – which can explain why many lonely people engage in conversation with strangers on public places, to fulfil their need of connection with others. This sociability is linked with the able body, when someone's physical capacity is taken away this can result in a violation of the identity and affect the notion of him/herself (Rokach *et al*, 2006). Our society is planned *by* and *for* able-bodied people, and this is not something new. With ageing, the associated disabilities and the fact that the elderly are not anymore part of the productive society, gives rise to feelings of sadness, anger, frustration and fear. Also, disability, most of the times, is routed with dependency.

The care users who participated in this research, were profoundly dependent on the caregivers to perform basic life tasks, and in the case of António, this dependency goes even further since they were his only connection with the community. Elders who are dependent, are more vulnerable to loneliness and boredom, since the declining of physical health results in a forced social isolation (McInnis & White, 2001). For those living in the nursing home, it would be easy to think that they would feel less lonely, bored or left out. However, the fact they live in a 'community' does not function, at least not totally, as a way of sociability that fulfils the life of the users. The relationships between care users and caregivers, in the case of nursing homes, are generally superficial. Although some of the caregivers described creating an emotional bond with the users, it is always with low levels of commitment – and this is also applicable to users who care is provided in their household – mainly due

to the notion that to be professional they cannot be too affectionate because of the risk of creating a co-dependency that may endanger their work and their mental health.

In her research on the experience of loneliness in a nursing home Cátia Leitão has written about the meanings of knocking or not knocking on the door of the room/house of the care user (Leitão, 2015). Knocking before entering is a basic European rule of good manners. In the case of home care providers, although in most cases they had the key, they would always knock first on the entrance door and after that, in the cases applicable, at the door of the room where the elder was likely to be. Thus, even if they visit those persons every day, they are never in a position of power or total comfort, but they are always entering private property. Independently of the level of dependency of the user, this rule was always followed in the case of the teams we accompanied, reflecting the idea of respect for the household and for the person. The situation was not the same in the nursing home, where whether or not this rule was followed depended on the degree of dependency of the care user. In the case of less dependent users, the teams would knock at the door, in the case of more dependent care users - those who had difficulties in communicating or were bedridden for example, they would enter the room without knocking. Even if this may seem a very mundane problem, not following this rule furthered the relationship of power and domination – even if not conscious – between the caregivers and the care users. If in a ‘normal’ context this would be interpreted as disrespectful treatment, in the context of a person living with disability this violation of individual privacy is overlooked.

Despite the effort made by the care workers to retain their emotional distance the dependency of disabled people seems to have a significant impact on their lives. As Kittay (2001: 565) discusses, ‘all caregivers, familiar or paid, become derivatively dependent when they turn their time, attention, and concerns to a dependent other’. We found that the fact that the teams are assigned to care for many users increases the stress associated with care work. Not only do they have to be efficient in what they do, in terms of quality and timing, but also they have to be emotionally ‘efficient’ meaning that they cannot overlook the feelings of the users, even if they do not like the person. Care work is, in its broad sense, very consuming work but in case of care of disabled persons the outcomes are different than they are in the case of care work in a nursery where the worker can observe improvements and results of his work in the development of the child including disabled children. Caregivers working with disabled seem more prone to experience poor working conditions (Kittay, 2001), especially in countries like Portugal, where the services are associated with institutions of ‘social solidarity’. We found that the use of the word solidarity, compounded by the fact that the institution where the ethnography was performed is a Catholic institution, encouraged a framework of charity and benevolence, that somehow those who cannot care for themselves must be protected and that it’s a moral duty for those women to perform that role. Women work outside the house now, and Europe’s economic crisis led Portugal to ask for a bailout and only increased the pressure of women to work outside the home. Furthermore, what in the past were tasks for the family are now ‘public’ and take place as part of the economy. The problem is that the economy is built to be constantly growing, to produce more. In the case of care work, increasing productivity can work against what is needed. For disabled people the amount of time needed to provide care is directly proportional to the amount of time the disabled need to perform a task. In the case of highly dependent individuals, the time needed depends on the care user’s situation at a particular moment: if the caregivers arrive at one time the person might only need help getting into bed, at another they might need a full bath and change of bed linen which obviously is more time consuming. It is simply impractical for care workers to increase productivity:

'There is a limit to the number of people one worker can care for without jeopardizing the quality of care that is provided' (Razavi & Staab, 2010).

Not only are care workers subjected to pressure to be productive but also their productivity is not adequately compensated for. As was previously noted, care work is still seen as something done for the satisfaction of helping someone, being a reward in itself rather than performed for the money. However, we found most of the care workers we talked to started working as caregivers *because* they needed to work and therefore to have an income. In most cases, the emotional reward of helping someone came with time. It could come to be important but a monthly income would (maybe) always be more important than simply being 'a decent person who take care of the vulnerable'.

The low wages associated with care work are a result of poor investment by the governments and the public policies and norms that regulate this kind of professional activity (Razavi & Staab, 2010). Added to that, the symbolic meaning of caring, as something 'natural' that requires neither knowledge, skills education, training nor experience (Razavi & Staab, 2010) increases the justification of the non-investment in the working conditions of the care workers. However, not all people are able to perform those task and poor working conditions discourages those who have the capacity from taking this professional path. This is reflected in care being reduced to a list of tasks with no room for personalized interaction. Also, the discontentment of workers with the wages lead to a small number of employee and little satisfaction in the work produced. Therefore, providing caregivers with the adequate conditions of work and a just compensation is a matter of justice, of compensating them for the intensity of their labour and the sympathy and empathy put into their performance (Bogdan and Tailor, 1992 in Kittay, 2001).

Home based care is the preferred type of care arrangement and it is usually 'mixed', partly commodified and partly performed by family and friends unpaid. Either way, care is both a collective social responsibility (as explained by the CaC approach, ETHOS Deliverable 5.1., p. 11) and also a moral obligation (EoC approach, *idem*). However, commodified care, whether or not it is home based, does not automatically translate into better care than non-commodified care. The integration of Portuguese women into the labour market altered the social structure of care, and transferred both the physical and emotional aspects of care to other women. As Claassen (2011) explains, to care for a person isn't the same as 'caring about' and commodified care finds many obstacles in this regard. The care workers that participated in this research both 'care for' and 'care about' as they seem to be good examples of caregivers. António, Susana and Paulo indicated that there are workers who only 'care for' and don't 'care about', meaning that the emotional bond between the care user and the care worker is important, and the fact that they are being paid for care doesn't mean that the worker will inevitably create a bond with the elderly. On another side, just because a person is related to the care users also does not mean that they will provide good care; people 'exercise their agency in caring for others' (Claassen, 2011: 47). One thing that cross-cuts the experience of care users and care workers is that commodified care is necessary, even if it sometimes complements informal care as in the case of Alexandra's mother. However, what seems to be difficult in the achievement of fulfilling lives for careusers – especially those without extended family – is that there are dimensions of care that aren't commodifiable (Lynch, 2007). Feelings cannot be paid for and the empathy between care workers and care users is a privilege. When this does happen both sides of the relationship of care understand each other. That's why, the general claims for justice in this context were related with time: not having time to 'care about' the users, not having time to spend with family and friends, not being able to *be* with

the users in such way that they would be capable to respond to their needs and help them to be recognized as full members of society and have the life they want.

## 5. CONCLUSIONS

Like other European countries Portugal faces considerable challenges regarding its capacity to provide care. As in many others countries, the basis of Portuguese care for dependents (elderly, children, persons with disabilities) relies on the family, but when the family can't be present in the life of those in need, the obligation lies with the state to provide solutions to cope with the necessities of this part of the population. The research published in 2012 by the European Commission shows that in 2007 out of 20.7 million elderly dependents, 8.4 million received formal care, and 12.3 million were provided with informal care. This, together with multiple other factors, suggests that it is necessary to demand from the Portuguese state a stronger effort to expand the network of continuous and palliatives care provision – not only the number of places available but also, the number of care workers to be hired and their access to decent training.

We found that care workers, besides being unaware of their legal rights and protections, were not even considered as *formal care workers* but 'only' auxiliaries. Given that most of the commodified care work in Portugal is performed by women with only compulsory school education, most of them are in this position, precisely because they did not have the desire or opportunity to continue studying. Nonetheless, in practical terms, the work they performed is of critical social importance, and people who have one or more dependents would be left alone with their elder/person with disabilities, if those women didn't exist. Our work suggests that the cooperation established between the state and the IPSS is quite fragile. The private institutions do not have the human, logistical and financial resources needed to guarantee quality care to all its users; on the other hand, the state sidesteps responsibility, supporting these institutions through social security contributions. Thus, IPSS has to deal with an ever increasing number of care users under all types of arrangements, without the possibility of increasing staff numbers. To help users achieve their full potential it is crucial that carers spend more time with them and caring about, not only caring for. However, when the main emphasis of state policies, is to construct new care policies or alter existing ones, neither care users nor caregivers are heard. The decisions are made top down, with policy makers not listening to those who are in need of the care and those who provide it.

Tables 5 and 6 systematize the types of injustices identified during the ethnography. It seems that there are no differences in the injustices identified in private homes vs institutions, both for care workers and care users, since the configuration of work and conditions were almost the same.

For care users, the types of injustices were mostly related to isolation and non-participation in the community. Care users in the home care system had the advantage of not suffering from being in an environment that isn't their home, for some being at home might not be a good idea, especially if their disability restricted their movements and they lacked familial support. For example, in the case of Mr. António, institutionalization – even if only during the day, as the care workers suggested – would be preferable in terms of sociability and security. Although the sensation of loneliness seemed present in all the situations, the fact they enjoyed some moments of conviviality on a daily basis – mainly during

meal times –helped the elders to feel less alone. In the case of the caregivers, there seems to be no difference between the injustices identified in the teams who worked in the home care system and in the institution. In both cases, the low wage, overload of work and the emotional/ psychological stress was a constant.

Social aid can be considered as an ‘interactive concept that refers to the transactions that are established between individuals’ (Barron, 1996) and has to be considered when thinking about a European theory of justice, when it is understood as a social construction or contract, rather than a “timeless truth” (ETHOS application: 20). Constructing a new theory of justice is to give voice to all citizens, to those who for many years haven’t be heard, and are dominated due to their vulnerabilities.

**TABLE 5 - Injustices lived by care users**

Care users
Home care & institution
Infantilization
Paternalism
Loneliness
Inequality

**TABLE 6: Injustices lived by caregivers**

Caregivers
Home care & Institution
Overload of work
Emotional and psychological stress
Absence of professional formation
Low wage

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