

To Care for or to Care about? Justice and Injustices in Commodified Care Work

Cuidar de ou preocupar-se com? Justiças e injustiças do trabalho de cuidado mercantilizado

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TO CARE FOR OR TO CARE ABOUT? JUSTICE AND INJUSTICES IN COMMODIFIED CARE WORK

Abstract: In Portugal, cooperation between the state and non-governmental organisations has led to the creation of institutions that provide care services, called IPSS [Private Institutions of Social Solidarity]. This paper presents the results of an ethnography carried out in a rural IPSS that provides care for the elderly. The fieldwork aimed to understand how claims for justice are negotiated between care workers, care users and employers. The objective of this paper is to contribute to the debate on redistributive justice by showing how inequality of income affects access to care as well as examining the idea of justice as a lived experience by demonstrating how claims for justice are depicted in day-by-day relationships of care. This paper is divided into two parts, the first being an introduction contextualising Portuguese care work. The second part focuses on António's story and reflects upon the work of two caregivers and their claim for justice.

Keywords: care work, elderly care, redistributive justice, welfare society.

CUIDAR DE OU PREOCUPAR-SE COM? JUSTIÇAS E INJUSTIÇAS DO TRABALHO DE CUIDADO MERCANTILIZADO

Resumo: Em Portugal, a cooperação entre o Estado e organizações não governamentais levou à criação de instituições prestadoras de serviços de cuidados a dependentes, designadas por IPSS – Instituições Particulares de Solidariedade Social. Este artigo apresenta os resultados obtidos através de uma etnografia realizada numa IPSS de uma zona rural que presta cuidados a idosos. O trabalho de campo tinha por objetivo entender como é que as reivindicações por justiça são negociadas entre os trabalhadores, os utentes e os empregadores. Este artigo tem por intuito contribuir para o debate sobre justiça redistributiva, mostrando como a desigualdade de salário afeta o acesso a cuidados, bem como examinar a ideia de justiça como experiência vivida, ao demonstrar como as reivindicações por justiça surgem nas relações quotidianas de cuidados. Este artigo encontra-se dividido em duas partes, sendo a primeira uma abordagem contextual ao trabalho assistencial em Portugal. A segunda parte foca-se na história de António, refletindo o trabalho de duas cuidadoras e das suas reivindicações por justiça.

Palavras-chave: cuidado de idosos, justiça redistributiva, serviço de cuidados, sociedade de bem-estar.

INTRODUCTION

The neoliberal way of thinking and its assumption that all services are best provided through the market (Lynch, 2007: 564) has led to the commodification of care work, overlooking the fact that the disparity of economic resources translates into unequal access to care and to inequalities regarding who provides care and who receives it. Although certain societal changes have taken place in various cultures, countries and societies, care work is still not fairly recognised as “work”, neither is it fairly distributed between women and men. In a European context, commodified care work often falls to specific groups of women – those with lower levels of education or migrants (*ibidem*).

This paper focuses on the life and working conditions of both care workers and care users in Portugal. Over the past few years, the discussion regarding elderly care in Portugal has focused on commodified and uncommodified care work (i.e., unpaid care work, mainly performed by family members, close friends, and acquaintances) and on the need to rethink the services provided by the welfare state, both in consideration of the nation’s ageing population. Analysing commodified care work in a nursing home allows us to better understand the current situation of redistributive (in)justice in the life of care workers and users, which may help stakeholders better understand the status of elderly care nationwide.

In this paper, I will present a part of an ethnography of care work that constituted the fieldwork of one of the study cases of the ETHOS¹ project. This ethnographic fieldwork took place in May 2018, which entailed following care worker teams along their daily routine. In the first part of this paper, I will be contextualising care work as well as the different types of care work practised in Portugal – with a specific focus on elderly care. I will then present part of the ethnography and discuss how some of the witnessed situations can show us the processes of labour exclusion of care workers and how redistributive injustices are present in commodified care work. Readers should bear in mind that this is only a small part of the reality of care work in Portugal and that the geographical context – in this case, a small city in the countryside – plays an important role in the situations exposed.

1. CARE IN PORTUGAL

After World War II, several European countries and other countries worldwide created a variety of welfare states intended to suit the specific needs of their people. Social policies and the welfare state were, in part, created to provide care for those in need, such as people with disabilities, children, or the elderly. Along the gamut of the different types of

¹ ETHOS – Towards a European Theory of Justice and Fairness. European Union’s Horizon 2020 programme under grant agreement No. 727112.

welfare state, Portugal has a very specific one in which responsibilities are shared between the state (“welfare state”) and the family (“welfare society”). In the words of Boaventura de Sousa Santos (1992: 52),²

[...] [the] welfare society intends to designate the networks of inter-knowledge, mutual recognition and mutual help based on kinship and neighbourhood ties, through which small social groups exchange goods and services on a non-commercial basis, with a logic of reciprocity

Even if families still play an important role as caregivers, particularly women, the Portuguese history of providing extra-familial care is no novelty. The history of extra-familial care in Portugal began before the 18th century, when health care was guaranteed by hospitals and religious associations (*Misericórdias*), closely linked to the Catholic Church. This connection between welfare and the Church continued throughout the dictatorship (1932-1974), whose agenda did not seek to aid the impoverished population. Hence, the Catholic Church was responsible for providing aid to those in need (Hespanha *et al.*, 2000: 120-121). After the revolution, in April 1974, it was necessary to restructure the social protection politics, thereby reinforcing the importance of the State’s intervention to reduce poverty. This restructuring process diminished the action of the prior traditional institution which at the time was named, *Instituições Particulares de Assistência* (i.e., Private Assistance Institutions). However, even before the beginning of the eighties, the Portuguese State understood that it did not have the economic power to support the social rights gained by the revolution, thus leading to the creation of the *Instituições Particulares de Solidariedade Social* (Private Institutions of Social Solidarity) (IPSS), in a process of privatization of Social Security (*ibidem*: 130).

The IPSS are non-profit private entities that provide care to those in need, working as an autonomous organisation with no administration from the State. The IPSS provide a wide range of services focused on the care of children, the elderly, and people with disabilities, offering solutions to those groups and responding to the needs of each socio-geographical context. The IPSS exercise great autonomy in terms of action, considering that they can choose which activities they want to develop; however, they depend on State funds. Nonetheless, due to their crucial importance with respect to the functioning of Portuguese society, they hold significant negotiation power (Hespanha *et al.*, 2000: 140). Their importance is emphasized in the Social Security Law n.º 28/84, dated August

² This and all translations are by me.

14th,³ which points to the development of the IPSS as a priority to the Portuguese government (*ibidem*: 138). Responsibilities are to be shared between the institutions and the government. On the one hand, the IPSS are responsible for guaranteeing the proper functioning of their services, giving priority to low-income groups, providing adequate and efficient services, ensuring the existence of human resources capable of guaranteeing the good functioning of the services provided, providing valuable information to Social Security for them to assess the services both qualitatively and quantitatively, and to enable the oversight by social security officials. On the other hand, the Portuguese state, via the Social Security system, provides the financial support (previously agreed between the parts, along with technical support) necessary to the proper development of services, enhances the staff's technical training, evaluates the services, and promotes cooperation between the IPSS and the State and between the IPSS themselves (Hespanha *et al.*, 2000). This cooperation is fruitful for everyone involved. The State is relieved of the institutions' administration and the civil society, in turn, has a network of care that is available. However, there are inequalities in the sector and the IPSS available are not evenly distributed throughout the territory. The less populated rural interior, where most of the elderly population is concentrated, fails to supply adequate structures to be able to provide quality care. This leads to two problems which I will demonstrate in the second part of this paper. Firstly, the demand is higher than the supply, which means that the care workers working for IPSS are overwhelmed with work and have less time to dedicate to each care user. Secondly, care workers hired by the families tend to demand high salaries, which is most of the time incompatible with the families' income and the care user's retirement allowance. As I will explain through the ethnography, this incompatibility, along with the high demand for Social Security services, leads to the abandonment of the elderly and other dependent people, those who receive just the minimum care to survive through home support services.

Care work is a highly gendered work, mainly performed by women, and in Portugal this is by no means different. In a society built upon patriarchal stereotypes, paid and unpaid care responsibilities are thought to be most suited to women. In Portugal, those women are mainly natives, even though some researchers (Peixoto *et al.*, 2006: 7; Wall and Nunes, 2010: 400) suggest that, in urban areas, several immigrant women work in private commodified care and IPSS. In this particular case, in Portugal's rural interior, there are few immigrants, mainly due to the lack of job opportunities, which justifies the predominance of white Portuguese women in this type of service.

³ Lei n.º 28/84, de 14 de Agosto. Diário da República n.º 188/1984, Série I de 1984-08-14. Lisboa: Assembleia da República.

It is common to believe that it is best for the elderly to stay in their environment, their house and/or where they feel comfortable. However, the Portuguese government has been reluctant to create the necessary conditions to allow the families to take care of their relatives and thus, for them to stay at home. The Petition n.º 191/XIII/2,⁴ presented in 2017 to the Portuguese Parliament, demands more support to informal caregivers as well as the reinforcement and diversification of the formal structures that can provide care and give relief to informal caregivers. This suggests that the IPSS need more financial support to be able to hire more care workers, especially for the HSS teams. If informal caregivers could be dismissed from their work when they needed to take time off to look after a relative and had the necessary financial support, perhaps fewer families would need to seek help from commodified care work, thus freeing up the institutions. Yet, as there is no empirical research on this topic, it is important to take into consideration that the work of informal caregivers is also subject to injustices, many of them being the result of the patriarchal and capitalist system. Financial aid to families with dependents is not enough to dismantle this system of gender inequalities, and it does not solve other structural issues, as in the case of small families in which the care work may be provided by only one person (usually, a woman), incompatibilities with profession occupation of the informal caregivers and also the drudgery of the tasks themselves that can make it more attractive for families to hire specialised staff to provide care to their dependent family member in order to relieve informal caregivers.

As José de São José shows, “intergenerational family solidarity is not in crisis” (2012: 1), what is in crisis is the welfare state and, in the case of Portugal, its partnership with the welfare society, which has been deteriorating since the economic crisis of 2008. On the one hand, some families cannot afford overpriced commodified care and must therefore take their relatives back home. When they cannot take good care of them, they are forced to leave them alone, which increases loneliness and decay. On the other hand, we have institutions accommodating people with complex needs, and they are not able to give their workers decent working conditions, inducing work overload and burn-out. As surveys (Alber and Köhler, 2004; Daatland and Herlofson, 2003) conducted in Europe have shown, in Southern European countries the preference lies with family care arrangements, with families favouring domiciliary care or day centres to enable the older person to stay at home: “putting the elder person in a nursing home is equivalent to giving them an earlier death” (São José, 2012: 4). Thus, it would seem reasonable to invest more in home care. Yet, despite the increase of services available for this sector in recent years, access to proper care services is still limited for most low-income families.

⁴ Petição n.º 191/XIII/2, de outubro 2016. Diário da República n.º 18/2017, II Série-B. Lisboa: Comissão de Trabalho e Segurança Social.

Furthermore, 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.

In the Portuguese context, care workers are physicians, nurses and gerontologists who work as caregivers in various settings – hospitals, nursing homes, continuous and palliative care networks, home support services (HSS) (Rodrigues, 2014: 28). However, the care workers who *actually* provided care to the elderly in the institution observed during the ethnographic fieldwork fall more under the description of Claassen (2011: 45): “a professional who is paid a wage by the care recipient or by a care institution for which he/she works”. For the purposes of this paper, I am considering *care work* as all the activities that make it possible for people to live in a comfortable, dignified way. This includes all tasks related to personal hygiene and food but also having a conversation with the care users, listening to them, and providing emotional and psychological support, promoting spaces and moments of sociability, especially for those who are more isolated. In the institution depicted in the ethnography, commodified care workers were called “helpers” or “collaborators”. Using, in this paper, the term “care worker” is an acknowledgement of the importance of their work and professionalism, regardless of whether they have a degree or not.

1.1. DEMOGRAPHIC INFORMATION

In 2017, a year before the fieldwork, Portugal had a resident population of 10.325.500. The life expectancy was 82 years for women and 75 years for men. The ratio of elderly (65+) per 100 young people was 7 to 148. There were, in 2018, 1 million people aged 75 or over, of whom the majority are women (Ministério da Saúde, 2018). Catarina Resende de Oliveira and some colleagues conducted a study, between November 2005 and April 2006, which revealed that the age group with > 75 years of age showed a functional dependence twice as high as other age groups (Oliveira *et al.*, 2010: 23). Men are more dependent (4.2. more than women) and one-fifth of the elderly spends eight hours or more a day alone (*ibidem*: 38).

Regarding the IPSS, between 2000 and 2015 the social assistance available increased by 72%, with a total of 111.000 new vacancies (GEP/MTSSS, 2015: 37). The users of HSS, such as the one described in the fieldwork, are aged between 75 and 89 years old, and 62% of them have some degree of dependency (*ibidem*: 44). Most of the care users of the HSS that I accompanied lived alone or were left alone for most of the day. The youngest of them was about 70 years old, and the oldest was approximately 80 years old. The majority of them could still walk and had some degree of mobility, even if they needed help. Yet a lot of them were bedridden with different degrees of incapacity. Elderly care users who required special care lived permanently in the nursing home,

which was part of the IPSS that coordinated the HSS. Being the less expensive home support, the nursing home was one of the last resorts for the users and their families.

1.2. CARE WORKERS' PROFILE

In Portugal, care work has always been associated with women, although before 1974 most women worked at home (domestic work, farm work and others) and not for a third party. In most rural and impoverished areas many of them started working as domestic workers from a very young age, most often as live-in maids, as a way to avoid hunger and poverty; in addition, it provided an opportunity to leave rural areas, avoid working in agriculture, and have a greater income (Wall and Nunes, 2010: 399). Today the nature of female employment has radically changed, as Portuguese women work mainly full-time outside their home. However, as it is the case throughout the world, their care responsibilities did not diminish, and for many families, the solution has been to find a third person, usually another woman or women, to help with the “domestic care”. This raises issues not only regarding the overload of care and domestic work but also in terms of gender equality since it is through the commodification of care provided by women that those other women can find independence in a male-dominated society.

Through a series of interviews with 18 care workers, both male and female working in an IPSS in the north region of Portugal, Maria Eduarda Ferreira (2012) draws a profile of care workers that is similar to the one I found during fieldwork. Most institutions offer no training for care workers, which is a barrier to the quality of the care services provided, and Ferreira (*ibidem*: 56-58) describes this as one of the main difficulties expressed by care workers. When questioned about the reason for choosing this profession, most of the care workers interviewed by Ferreira stated that they needed to “get a job” (*ibidem*: 49). As was the case with the care workers I accompanied, those interviewed by Ferreira had been placed in the IPSS by the State employment centres, even though some referred to previous experience with elderly care as a motivational factor. As to the teams of the IPSS where the fieldwork took place, the majority was sent to work in care institutions during the financial crisis of 2008 when many factories closed, leaving women with the lowest educational levels unemployed. This was a solution to keep these women in the labour market and to decrease unemployment rates. Unfortunately, most of them did not have access to a qualified professional status, which as I will explain, hinders the quality of care, and deters the IPSS's care workers from pursuing a salary increase since they are “competing” with nurses, physicians and gerontologists who have a degree and are therefore considered “formal caregivers”.

1.3. METHODOLOGY

The fieldwork was conducted during the ETHOS project research in 2018 for the work package focused on justice as a “lived experience”. It aimed at highlighting the gaps in European ideals of justice and fairness from the perspective of the groups that experience or are vulnerable to injustices. This specific task explored the accommodation of justice claims in the lives of physically disabled adult care users and the people who are paid to provide care in private households with attention to the role of gender and, where appropriate and possible, ethnicity. The methodology chosen for the fieldwork was a combination of mini-ethnographies and semi-structured interviews. In the social sciences, ethnography is the basis of fieldwork, and in this particular case, it was designed to observe, understand, and explore the relationships between the care workers and the care users in private households. The semi-structured interviews were performed to find more details to add to the ethnographies, and particularly to add information that was not possible to obtain through the observations alone. Due to privacy concerns, all names were changed, and when someone was referred to by the participants and/or intervened their name was removed. Ethical clearance was obtained through the analysis of the ethical commission of the Center for Social Studies, University of Coimbra (CES-UC). A letter and a consent form were presented to the administration of the institution in which the fieldwork was done, to get their approval. Finally, each participant of the research study received a letter explaining the study and what was asked of them, and their oral and/or written consent was given. I had with me a fieldwork notebook that I filled with information throughout the day, which I then completed with other information at the end of the day. Interviews were recorded and later transcribed.

2. ETHNOGRAPHY OF CARE – ANTÓNIO’S STORY

The fieldwork was carried out in an IPSS located in the rural region of Portugal, in a city of approximately 28 946 inhabitants. I had the opportunity to accompany an HSS team during their shift that normally took place every day, including weekends, from 8 a.m. to 4 p.m. A full shift normally includes a visit of six to eight houses, located a five-to-ten-minute drive from each other. I was present at all visits, and all of them were full of wonderful people who had a lot to tell. Equally interesting was the interaction between the care workers and the care user, as I could sometimes discern from the details of their dialogues which offered their perspective on their working conditions and the ideas of justice that surrounded this relationship. For this article, I chose to focus on Ana, Maria, and António. Ana and Maria are both care workers, women and 35 and 44 years old, respectively. They have been working in the HSS team for about 15 years at the time. António is 71 years old and is the care user whose case we will be analysing. António

lives alone and has some mobility issues related to severe rheumatism. Because he lives alone, he is visited three times a day by the HSS teams: morning, lunchtime and evening. The number of visits *per day* depends on the elderly family structure, the type of activities in which they depend on someone, and the analysis of the case made by the local services of social security that will articulate with the IPSS to establish the timetable of care. The lunchtime visit is the shortest and consists only of delivering the meal and ensuring that the person eats.

Even though accompanying Maria and Ana was not my choice, since they formed the team in charge during the period of the ethnography, I have chosen António among the other care users due to his situation, that we will see was rather peculiar, and for whom the services of the home support team were of great value.

2.1. GETTING TO KNOW ANTÓNIO

The ethnographic observation started on a Monday morning. I arrived at the institution by 7:30 a.m. A care worker from the night shift of the nursing home opens the door and tells me to wait for the HSS team in the locker room. The locker room is a space where both the nursing home workers and the HSS teams can change clothes. There is also a table in the centre of the room with three notebooks – two for the two nursing home teams and another one for the home support team – where the care workers are expected to write a report about what happened during their shift. This is meant to inform the caregivers who will begin the next shift and the administration about the work and about any problems that might occur. When Maria and Ana arrive, Maria addresses me saying that they were informed that I would accompany them and she welcomes me. After having changed their clothes, she goes to the main hall where there is a large cupboard. This is where all the keys from all the houses in the HSS network are kept, stored in a small plastic box, inside a drawer. Ana joins us right before we head to the back of the building where the vans are parked.

We leave the institution around 8:30 a.m. and we visit four houses until 10:17 a.m. These houses are visited every day always in the same order. When we arrive at António's house, he is already waiting for us. The house is located in a small street parallel to the main road, and it is dark and full of overgrown plants. When we get out of the van, the caregivers put on plastic gowns and gloves. As 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. They open the door and step in slowly, shouting "António?", but there is no reply. They mention the smell and comment on the house being dark, cold, and damp. We proceed down the hall; I follow them, feeling the

coolness of the walls, even though outside the sun is shining. 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 the bed is António, who looks at me and comments “One more?” I explain that I will be accompanying the girls’ for that week. He nods in agreement and asks no further questions about my presence.⁵ The caregivers begin the care routine, which is the same for all the care users: first, they sit António up, they undress him from the waist up and begin to wash him. First the hands, then the face. When it is time to start the intimate hygiene, I decide to leave to the hallway. When his hygiene is done, the caregivers help António to get dressed and help him to get up to eat his breakfast.

They slowly managed to reach the kitchen, and Ana has already set the table with his breakfast, milk, and bread, and has also washed the dishes from the previous day. António sits at the table and Maria puts the medication in a spoon for him to take and returns to the bedroom. Ana talks to him about agriculture. Maria returns and comments to Ana: “This smell is getting impossible”. Ana shrugs. António finishes his meal and they start to put the dishes away. They ask him if his sister has been visiting him, and he says no, that he has not seen her in a few days. Later on, Maria tells me that his sister has not visited him for weeks. António gets up and walks slowly to the living room, where there is a sofa and a television. Ana begins to collect the laundry and the garbage. Maria helps António sit on the sofa and makes him as comfortable as possible, resting 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. They decide to take the clothes with them, despite going against the regulations.

The visit finishes with the care workers completing a table that describes the care performed in each house. When we leave the house, I recall a moment during breakfast when António said he was afraid of thieves. Maria explains that, as his health has deteriorated, the institution’s administration decided to take measures to ensure his safety. About a year ago, the HSS teams were asked to lock most of the drawers, hide knives, lighters, matches and turn off the gas when they leave the house.

António does not receive any visitors, and neighbours pay him little to no attention. “He looks like a stray dog”, Maria tells me with some sorrow in her eyes. “The only people he sees all day are the care workers [i.e., the HSS team]”. I ask about his sister. Maria tells me she does not know where she lives. All she knows is that it is not nearby and

⁵ After this, I talked to him, explaining what I was doing there and asking for his consent to participate in the study.

that she never or rarely visits António. The care workers started hiding things from him for fear that he might hurt himself or cause an accident: “His hands are very shaky....and he has become forgetful. Imagine he leaves the oven on! An explosion would blow up the entire neighbourhood”. I ask for her opinion on António’s current situation. She believes António cannot be by himself anymore, and he should be selected to live permanently at the nursing home or, at least, go every day to the day care centre to socialise and be monitored. Both Ana and Maria fear that his isolation might result in a deterioration of both his physical and mental health.

When I try to understand why he does not go to the day care centre/nursing home, Maria explains to me that the decision to take him as a day care patient is in part the responsibility of Social Security, as it is up to them to decide if a user needs to be accompanied or not during the day, night, or both. This is closely linked to the independence of the IPSS and their administration’s management of their users and the services they can benefit from (Hespanha *et al.*, 2000). Maria and Ana agree that António should at least be enrolled in a day care centre or nursing home as, in their view, he does not have the physical or psychological conditions to be home alone. Since António lives alone and receives a small pension, the decision to provide him with the right care service depends, to some extent, on the local Social Security services. According to Maria, Social Security could and should ask for his institutionalisation but “there are few vacancies, you know...and I guess he does not have a big retirement benefit”. In the cases where financial difficulties are present, Social Security covers part of the expenses of institutionalisation, but the demand is considerably higher than the vacancies available. This means many elderly people are home alone most of the time.

When we arrive at António’s house at lunchtime, he is in bed. Ana wants to know why. He explains that he was sleepy and cold. Anna encourages him to get up. Slowly, António heads to the kitchen and sits down. Meanwhile, Ana has already served the food and a glass of water and impatiently waits for him, playing with the keys to 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.

We then 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 is always on home support. I want to know what she thinks about António living alone and seeing nobody besides them:

It is a big responsibility. We are the only people he sees all day. If anything happens, we will be the ones to deal with it. There is no family, the neighbours do

not care...it is hard knowing that we can arrive, and he can be hurt or...worse...we will always fear that, when we open that door, he will be dead.

Once the round is finished, we go back to the institution. It is the employees' lunchtime. In the main hall, a long table is set. We sit down with the other caregivers, and there is very little talk. After lunch, the teams resume work, as they only have about one hour's work left ahead of them. Maria explains to me that during that time they will not do much. They will visit a couple of houses and do some personal hygiene care and nothing else: "We do not have time. The next ones will deal with the rest". In the afternoon they do not visit António, so I had to finish the observation for that day.

When I arrived the next day, Maria was already in the locker room. The caregivers are talking about António. In "the book" it says that the afternoon team found the lock on António's door damaged. Maria explains: "they thought that maybe someone had tried to rob the house, but a neighbour told the girls it was him [António], trying to open the door. He wandered in the garden and went back to the house". It is worth noting that while Maria and Ana said that António's neighbours did not want to get involved, it was a neighbour who told the caregivers what happened, which suggests that they do pay some attention to him, even if they prefer not to get involved in his life. The caregivers are apprehensive about the situation. Maria says to me: "I hope we do not find anything worse this morning".

When we arrive at António's house, we see the door is half-open. Maria says once again that she hopes nothing bad has happened, and António is in bed, sleeping. Maria and the other caregiver enter the bedroom, waking him. Maria asks what happened with the door, and he explains that he wanted to go outside. Maria looks at me; she does not know what to say. They begin the routine of hygiene care, while they explain to him, "You know that you cannot leave the house alone". António answers: "I do not leave the house! Neither alone nor accompanied!" Silence. The caregivers do not insist on the subject. 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 he cut the string with it". Maria grabs the knife and goes back to the kitchen. I thought she would talk to António about this, but she passes behind him and hides the knife in the cupboard. She looks at me and says, "Now he does not know where it is". António continues to eat passively, not paying attention to what is going on around him. As in the previous day and the other days before that, Maria and the other caregiver take António to the living room after he finishes his breakfast. 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 shut and say there is a key to the kitchen door. They decide they will write down that information in the notebook if no one comes to fix the door.

2.2. BEING A CARE WORKER – CARING FOR AND CARING ABOUT

At lunch, Ana, whom I join again after the break, confesses that being a caregiver is physically and psychologically exhausting for her. Although she has tried in the past to distance herself from what was happening, she feels more sensitive now. She says now she realizes that “the reality of the elderly I care for will be my reality, my future”. She explains she now tries to focus more on what she does and to give the best she can: “loneliness kills, you know”.

Both Ana and Maria have been working in the institution for about 15 years now and neither of them has worked in any service other than HSS. Both defined their relationship with the elderly as healthy, even though they found it troubling in the beginning:

In the beginning, when we meet the elderly for the first time, it is always a bit difficult. [...]. They are bothered by our presence and our touching them. Imagine having two strangers come into your house and washing you? They are no longer children, but I think I have a good relationship with all of them. We gain more confidence with time, we begin to know more about them, about their families...it is all a matter of time and being alert, listening to them and their needs.

Maria and Ana admitted that they did not know anything about the law that protects caregivers. Both of them explained what they knew about the 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 access to it when they first started working at the institution:

“Hum...no...we learned through practice...by seeing others do it. Sometimes we have training, but it has got to be on our days off, and I think that is a bit unfair [...].”
[Maria]

The absence of training goes against what is stated as an obligation of institutions, as employers, in the Collective Agreement between the National Confederation of Solidarity Institutions (CNIS) and the National Federation of Workers Unions (Boletim do Trabalho e Emprego, n.º 31, 22/8/2015). In Chapter II, Clause 10, one can read that “The employer’s duties are: [...] e) to contribute to raising the worker’s level of

productivity, namely by providing professional training” (*ibidem*: 2529). Further on, in Clause 97, it is stated that:

- 1 – The institution must provide the employee with professional training actions that are adequate to their qualification.
- 2 – The employee must diligently participate in professional training actions [...].
- 3 – The training actions must take place during the normal working period, whenever possible, counting the respective frequency for all purposes as effective time of service” (*ibidem*: 2546).

And this last point was precisely one of the sources of tension between caregivers and employers, as Maria explained above. As it is not possible for the training to take place during the normal working period, the training, when available, was during days off, a situation considered unfair as it means that the workers could not enjoy their free time.

Both caregivers stated that they preferred to work on the HSS teams rather than in the nursing home – although they did not have this experience, they had an opinion based on what they heard from the colleagues with whom they eat lunch. For them, the worst part of working in private households is getting used to the space and to working in other people’s houses:

At first, I always feel a little bit shy...I do not enjoy going into other people’s houses, but I got used to it, I try to pretend it is a relative’s house. For me, it is the easiest way to deal with it...to think he is my cousin, and that I am going to visit him [Maria]

For Maria, the biggest difference between working in a household and other jobs is the intimacy:

It is different because it is way more personal, more intimate. This is not my background, but for some colleagues who came from the factories, this is much more personal. In the factory, they were all together, but it is not the same as being in someone’s house every day. It is more intimate.

What they find particularly difficult is to witness how the care users are becoming more frail and to know that some of them are always alone. They are worried about what might happen to them between visits: “[...] the worst thing is to see them getting weaker. Sometimes the changes are small. One week they can turn themselves over in bed but

the next they cannot. There are those who can still bathe themselves and then suddenly need our help for everything” [Maria].

When I asked if they had any conflicts with the care user/family, Maria explained that they never experienced any family complaining to the administration and that they usually solve the problem with the elderly and their relatives:

There was this one time when a lady’s husband got mad at us because his wife was complaining about the way we were moving her...the point is, when the bed is not specially adapted, we cannot always do things in the most delicate way, but I am certain that we were not hurting her [Maria]

Maria had to tell 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 do not like to do this to her, but we do not have an alternative. If you prefer, you can do it yourself and we leave”. After her intervention, the husband left the room and simply asked them to be gentle with his wife.

As Claassen (2011) explains, caring for a person is not the same as “caring about” and commodified care encounters 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 and other care users stated that there are workers who only “care for” and do not “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 does not mean that the worker will inevitably create a bond with the elderly individual. In the same way, just because someone is related to the care user does not equal quality care, as people “exercise their agency in caring for others” (*ibidem*: 47). You cannot buy feelings, and the feeling of empathy between care workers and care users is a privilege. When this empathy does exist, both sides of the relationship of care understand each other. That is why the majority of claims for justice in this context were related to time: not having time to “care about” the users, not having time to spend with family and friends, not having time to be with the users in such a way that they would be able to respond to their needs and help them to be recognised as full members of society and to live the life they want.

For the rest of the 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 that week. When we arrived, the lock was fixed. We come inside; António is lying down in his bedroom with the lights on. During hygiene care, Maria wants to know who fixed the lock. António says it was his brother-in-law who visited him the day before. On that day and for the

rest of the week, the visits proceeded as follows: the caregivers help António to get up; they serve him his breakfast and then accompany him to the living room, leaving the door closed. The specific nature of the HSS implies a certain repetitiveness, following a routine, with no room for improvisation. Any change in plans delays other visits and impacts the care given to the remaining elderly. Fortunately, as I was informed, in most of the houses that were visited, the elderly had a family member with them, using only HSS services for the provision of hygiene care.

2.3. JUSTICE AS A LIVED EXPERIENCE – CHALLENGES, CLAIMS AND SOLUTIONS

Care work is a career that is not suitable for everyone, and as we have seen, it is performed mostly by women. As another caregiver explained during the week, men are not employed in this institution as care workers. In her opinion:

Women are more fit for the task...and most users do not like men. We had a man working here once, but he did not stick around. Women care users refused to be washed by him and I think it is a natural response. They will not get naked in front of their sons, imagine in front of a stranger.

The care workers I worked with on this research told me and demonstrated through their behaviour that although they think care work is hard, their professional life brings pleasure to their everyday lives. Knowing that they are valuable and of service to someone gives them a sense of accomplishment.

One of the biggest problems for the care workers who participated in this research is the lack of knowledge about the law and the policies concerning their work. The Portuguese legislation on care is not particularly coherent and, from what I have observed, the employers did their best to comply with the law. The problem is that the care workers did not seem to know to whom they should address their demands. Care work seems to be stuck at a crossroad: on the one hand, care workers are highly respected for their work, mostly due to its emotional aspects; on the other hand, investment in the sector is still deficient, as was evident from the workers' lack of training and their low income, as they are paid the minimum wage, which was, at the time, 649€. The demands for justice made by care workers were sparse and vague, and they accepted the low salaries paid in their profession. The IPSS seem to have forgotten that these care workers are part of this work chain.

The expression “right to” seems to be recurring in the care workers' discourse since they know their rights and duties. However, they find it difficult to make themselves heard, as the members of the administration (social assistant, gerontologist, and others)

are overwhelmed with bureaucracies, alienating them from the real dynamic of the institution. At times, during breaks and when they were alone, the care workers talked about “going to tell the administration what is going on between the workers [regarding issues with the laundry staff and others]” but, as far as we know, that never happened. The care workers complain not just about their low income, but also about the workload. However, they keep these conversations to themselves, which proves the limited capacity they have to solve the issues they face. This reflects a loss of trust in the State’s institutional capacity to guarantee redistributive justice.

Equality, particularly equality of opportunities and equality of treatment for the care users, is very significant to the care workers. For them, the fact that some users have a nice house, a family and somebody to care for them between their visits strikes them as unfair to those who lack this support. This gap of opportunities leaves the workers restless, and the solitude in which some users live makes them feel distressed and responsible for those people.

Conflicts around time are recurring in the working lives of care workers. The workers referred to the limited time they have for each care routine, having to rush between users and getting nervous if, for any reason, they need to spend more time with any one of the individuals. In other research with commodified care work, the same question arises: “the lack of time to perform the task and the lack of resources available were referred to as obstacles to the provision of care” (Barbosa *et al.*, 2011: 125). Conflicts regarding time are also related to the general work overload and the resulting psychological stress.

Symptoms of stress and burn-out are well known in this profession and most of the caregivers working in the institution have shown symptoms related to anxiety, stress, and depression. Although in this case, they do not work overtime, the caregivers find it difficult to go home and be fully relaxed, as the problems presented by the care users will go home with them. To overcome this, the care workers came up with 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 altogether; the other solution, which relates to the previous one, was to hire more care workers, allowing them to spend more time with each user and allowing the rotation of shift schedules so they can have more rest. Unfortunately, in the case of the IPSS, this can only happen if there is more investment from the state or private investors. For the IPSS described in this ethnography, a part of their budget comes from donations from the Catholic Church and other individuals, considering the IPSS’ strong religious tradition. It is therefore difficult for the Administration to get the funds necessary to hire more workers.

DISCUSSION AND CONCLUDING REMARKS

The care users who participated in this research were profoundly dependent on the caregivers to perform basic life tasks. In the case of António, this dependency goes even further since they were his only connection with the community. The elderly in a state of dependence are more vulnerable to loneliness and boredom, since the declining of physical health results in forced social isolation (McInnis and White, 2001). Although some of the caregivers mentioned creating an emotional bond with the users, they do not like to over-commit, mainly due to the perception that to be professional they cannot be too affectionate as they risk creating a co-dependency that may endanger their work and their own mental health. This is also true for the users whose care is provided in their households.

Despite the efforts the care workers make to keep their emotional distance, the dependency of disabled people seems to have a significant impact on their lives. As Kittay (2001: 565) considers, “all caregivers, familiar or paid, become derivatively dependent when they turn their time, attention, and concerns to a dependent other”. 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 they must be emotionally “efficient” too, meaning they cannot overlook the feelings of the users, even if they do not like the person. Care work is, in a broad sense, very consuming work, but in the case of care of aged dependent people, the outcomes are different from what they are in the case of care work in a nursery. In this case, the worker can see improvements and the fruits of his/her labour in the children’s development, even with disabled children. The caregivers who work with the disabled seem more prone to experience poor working conditions (*ibidem*: 561), especially in countries like Portugal, where care services are associated with institutions of social solidarity. We find that the use of the word solidarity, combined with the fact that the institution where the ethnography was performed is a Catholic institution, encourages a narrative of charity and benevolence, implying that those who cannot care for themselves must be protected and that it is a moral duty for those women to perform that role. Tasks that, in the past, were of the family’s responsibility are now “public” and a part of the economy of a capitalist system structured to generate never-ending growth, always producing more. Concerning care work, increasing productivity can work against what is desirable. For disabled people, the amount of time needed to provide care is directly proportional to the amount of time they need to perform a task. In the case of highly dependent individuals, the time needed will depend on the care user’s situation at a given moment: at a given point, the person might only need help to get into and out of bed and later, with sudden changed circumstances, they might need a full bath and change of

bed linen, which is more time-consuming. It is simply unfeasible 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 and Staab, 2010: 411).

Not only are care workers under pressure to be productive, but their productivity is also not adequately compensated for. As was previously noted, care work is still seen as something done for the individual and the moral pleasure of helping someone, being a reward in itself rather than a job. A social organization supported by moral obligation could serve as a subterfuge for the exemption of contract workers’ rights. After all, if “helping” is a moral obligation, there is no need to comply with all labour rights, and that includes a fair remuneration. However, most of the care workers in this research started working as caregivers because they needed an income following a situation of unemployment. In most cases, the emotional reward of helping someone came with time. Being a decent person who takes care of the vulnerable is important but being able to provide for them and their families was as important, if not more.

Low wages in care work provided through IPSS are a result of poor investment by successive governments and of the public policies and norms that regulate this kind of professional activity (*ibidem*: 419). Furthermore, this paradigmatic understanding of caring as something “natural” that requires neither knowledge, skills, education, training nor experience (*ibidem*: 412) helps justify the under-investment in the working conditions of the care workers. However, not everyone can perform these tasks, and poor working conditions discourage those who can take this professional path. This is evidenced in the fact that care is reduced to a list of tasks with no room for personalised interaction. Providing caregivers with adequate working conditions and a fair salary is a matter of redistributive justice, of rewarding them for the intensity of their labour and the sympathy and empathy put into their performance (Kittay, 2001: 573).

Like other European countries, Portugal faces considerable challenges regarding its capacity to provide care. Portugal’s welfare society is structured so that care is provided through family members and acquaintances. This is a source of problems if and when the family cannot be present in the life of those in need. This emphasises the obligation that lies with the State to provide solutions to cope with these necessities, especially in an increasingly ageing society. However, the IPSS also has its obligations, promoted by the collective agreement between the National Confederation of Solidarity Institutions (CNIS) and the National Federation of Workers Unions (Boletim do Trabalho e Emprego, n.º 31, 22/8/2015) and in the case of the institution portrayed in the ethnography, they are not fulfilled in their entirety. The institutions, as employers’ entities, have the obligation to “[...] organise the provision of work in order to obtain the greatest degree of compatibility between the family life and the professional life of their workers” (*ibidem*:

2528), something which was not always complied with, and which was claimed by some of the caregivers. Regarding any obligations related to wage, working hours, meals time, vacations and shift work, the institution did not appear to be in breach, being the target – in the words of the caregivers – of various controls to ensure compliance with employer obligation. The obligations defined by the collective contract promote decent and fair working conditions, although with respect to wage, renegotiation at the level of the collective contract is difficult because it is based on the argument that these institutions do not have the financial capacity to pay like another company that generates profits. It will be pertinent, for further research, to understand what the leaders, employers and trade union representatives might view as the biggest failures in fulfilling the obligations and the reasons for them.

The story of Ana, Maria, and António shows that care workers, besides being unaware of their legal rights and protections, are not fully recognised as formal care workers, but only as helpers, which diminishes their importance in the network of care work. The work performed by those women is of critical social importance, and without it, people who are responsible for someone who relies on them would be left alone with their elders/persons with disabilities. Redistributive justice can be improved through a better relationship between the state and the IPSS, who alone do not have the necessary human and logistical resources to guarantee quality care to all its users in an equalitarian way. This means they give priority to those who can pay, which is an unjust state of affairs. The IPSS has to deal with an ever-increasing number of care users, under all types of arrangements, sometimes without the possibility of increasing the number of staff members. For care users to live a good life, whether they are disabled, elderly, or children, it is crucial for carers to spend more time with them to be able to care *about* them, not only caring *for*.

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