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CARING FOR AN ELDERLY PARENT  
SUFFERING FROM ALZHEIMER'S DISEASE.  
AN EXPLORATORY STUDY IN PORTUGAL

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2012

## **Caring for an elderly parent suffering from Alzheimer's disease. An exploratory study in Portugal**

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### Abstract

Portugal, like other European countries, experiences an increase in the number of elderly persons suffering from Alzheimer's disease (AD). Families, often called upon to provide and manage caring tasks are strongly impacted. To care for a parent suffering from AD is a radical example of relatives engaged in care for a person with a chronic disease.

This paper explores how adult children experience and adapt to the unexpected and demanding situation of a parent suffering from AD. It is mostly one child who becomes the main carer and sets up a care arrangement. In this paper we review existing care arrangements and analyze them from a work-life balance perspective. We highlight how in order to reconcile work and care those care arrangements often combine informal and formal care, in and outside the home.

In conclusion, in Portugal family care is central, though often complementary to paid care. Adult children have to invent strategies and to define their new role, in face of profound changes in daily routines as well as social interactions. The care situation has tremendous practical and emotional consequences and implies many adjustments for the carers. But at present existing health and social policies fail to provide proper support to this growing phenomenon.

*Keywords:* eldercare; social care; Alzheimer's disease; reconciling work and care; Portugal

## Resumo

À semelhança do que se tem verificado noutros países da Europa, Portugal regista um número crescente de pessoas idosas que sofrem da doença de Alzheimer (DA). Esta situação tem consequências importantes para as famílias que, frequentemente, assumem o papel de cuidadoras. Cuidar de uma pessoa com a DA é um exemplo extremo de uma situação de doença crónica.

O objetivo deste artigo é a caracterização, no contexto particular de Portugal, da situação dos filhos que tratam de um pai/mãe com a DA. Pretendemos analisar a experiência dos cuidadores, ou seja, como vivem e lidam com este novo papel muito exigente.

Através de entrevistas qualitativas com filhos cuidadores de um pai/mãe com a DA procuramos identificar os padrões de cuidados desenvolvidos e as suas implicações para as famílias na perspetiva de como é que estas conseguem conciliar as duas responsabilidades de trabalhar e cuidar, procurando várias fontes (formais e informais) de apoio.

Em conclusão, em Portugal os cuidados familiares são ainda centrais, mas sempre mais em complementaridade com os cuidados pagos. Os filhos adultos têm que definir este novo papel, sendo confrontados a mudanças profundas nas rotinas diárias, assim como nas interações sociais.

Cuidar de um pai/mãe com a DA têm muitas repercussões não só práticas mas também emocionais e necessitam números ajustamentos por parte dos cuidadores. As políticas sociais de saúde e da família ainda não conseguem oferecer o apoio certo e suficiente em frente a este fenómeno que vai crescendo.

*Palavras Chaves:* cuidados familiares; pessoas idosas; Doença de Alzheimer; conciliação trabalho e família; Portugal

# **Caring for an elderly parent suffering from Alzheimer's disease.**

## **An exploratory study in Portugal**

Sanda Samitca

### **Introduction**

Since Alzheimer's disease (AD) is a risk linked to age and our societies are demographically marked by an aging phenomenon, we can expect a dramatic increase in the number of elderly persons with AD in the years to come. In 2008, AD afflicted more than ten percent of the world population with 65 years of age and over. This adds to 6.1 million persons in the European Union and more than 15 million worldwide. Consequently the question of who will care for persons suffering from AD is of key importance and is a challenge for future health and social policies.

Due to medical progress since the end of World War II there is an increase in the number of diseases with a chronic evolution. The structural features of such diseases (i.e. long term aspects of the illness, uncertainty of its development and absence of treatment) weigh heavily on the sufferer's daily life. Chronic disease and its aftermath are often experienced as a (biographical) "rupture" (Bury 1982; Charmaz 2000). For the patient and his/her family, the situation involves the experience of a series of constraints on the level of treatment and everyday life, a loss or decrease in life quality, which can also undermine one's self-image. Chronic disease influences many facets of life, often disrupting patterns of social and family organization. As a consequence, ill persons and their families have to live with and manage their illness day-by-day. Chronic illness is characterised by the requirement of help from the primary family group. Thus, family members not only experience the aftermath of the situation, but are often required to take on the role of carers. In a situation of chronic illness, most of the time the care role falls to family members – spouse and/or adult children – except for acute phases, and takes place outside care institutions.

As a matter of fact, due to its characteristics AD, the most common form of dementia, can be considered as an extreme case of chronic disease, for which family involvement is crucial (Clément 2000; Pierret 2003). It is a neuro-degenerative brain disease, characterised by the slow, progressive and irreversible loss of cognitive functions, followed by behavioural troubles leading to a state of complete dependency. The

progression and length of the disease may vary widely. AD is characterized by light troubles of memory and speech, a change of personality in the early stages, confusion, behavioural troubles, as well as some difficulties with day-to-day activities. Tensions and misunderstandings with relatives may emerge, when the latter become aware of changes in the personality of the ill person, often without understanding their origin. Thus the establishment of the diagnosis ends the period of doubt and uncertainty and allows family and relatives to react. Total commitment in a long process of learning and adaptation may ensue, with the aim of keeping and caring for the person at home. However, the issue is how to provide care to a person suffering from an incurable disease, whose treatments address only the symptoms?

The situation of caring for a parent with AD is a radical example of relatives engaged in care for a person suffering from a chronic disease and its consequences. AD disrupts routines and habits, modifies the ill person's personality and behaviour, and transforms his /her interactions and communication. In sum, AD deeply modifies a person's relationship with the world, as well as his/her social and interpersonal interactions. On top of this, AD is also a hard challenge to familial solidarity and, in this sense, the study of AD and its implications not only for the ill persons, but also for their families is of a major importance for sociology.

This paper aims to examine the situation of adult children caring for an elderly parent suffering from AD in Portugal. In order to do so we will identify and analyze a) who, how and through which process one person became main carer; b) the main care arrangements set up by the carers; and c) the consequences of working and caring at the same time. After a brief literature review, we outline the research design and sample selection processes, and then introduce the main findings.

### **Literature review**

Social sciences research on dementia has mainly focused on the effect of stress and burden for persons providing care (Pratt et al.1985; Duijnste 1994; Anthony-Berstone et al. 1998; Clyburn et al. 2000; Bédart et al. 2000). Those studies underline the risk of stress and burnout of carers as a consequence of the heavy demand put on both their personal and social resources. In fact, carers' health is influenced both physically and psychologically (Whitlatch et al. 1997; Schulz and Beach 1999; Gonzales-Salvador et al. 1999; Yee and Schulz 2000; Hooker et al. 2002; Cohen 2002) by this role and activity of care. This approach has been widely developed mainly in the United States, notably

following the studies of Zarit who present the carers of persons suffering from AD as the "second victims" of the disease (Zarit et al. 1985; 1986). Research on the carers' burden underlines the importance of the development of support facilities for relatives, also called respite care. Although very influent, this approach is somehow simplistic (Abel 1990; 1999; Joël 2000) since it focuses only on the negative aspects of the situation and omits to consider the whole experience of the carers with its good and bad aspects. More recently, research on AD began to focus on the cared-for persons, considering care as a dynamic co-construction between cared-for person and carers, analysing the experience of persons suffering from AD, how they manage to negotiate and (re)create a sense of self and identity ruined/harmed by the illness (Graham and Bassett 2006; Hulko 2009; Westius, Kallenberg and Norberg 2010). This literature emphasizes the micro level of interpersonal contacts which is fundamental when considering care as an interactional process. A few authors also focus specifically on the transition of family member into the carer role (Sletzer and Li 2000; Quinn et al. 2008; Ducharme et al. 2011), examining how he/she faces up to the situation and assumes this new role. This approach draws attention to how families react to AD and what are their needs. The aim of these studies is to understand the coping resources and strategies of the carers entering this new role. Particular attention is given to the kind of information and support they receive stressing how poor and insufficient it was.

In sync with this approach, the aim of our study is to understand how families react and organize themselves when one of their members is suffering from AD. In the European context of social and demographic changes i.e. aging population, low fertility, increasing number of women on the labour market, the consequences of this illness in term of loss of personal autonomy and needs in terms of care are yet to be investigated. This situation has consequences on all aspects of the carers' life. Thus the objective here is to widen our research focus completing the experience and organization of care, with a specific focus on the issue of the work care balance.

### *Work/care systems*

In most Western countries, ageing at home is still highly valued. However, reality is often a mixed care model made of family and care services (public and private). Various forms of care scenarios can be distinguished: from a situation of no policy and a stress on the private responsibility of family; a policy where formal care is available, relieving the carers from hands-on tasks; a policy that provides support to carers not so much in order

to replace them or share the responsibility of care provision, but mainly to ensure the continuity of their commitment to care (Kane and Penrod 1995; Pfau-Effinger and Rostgaard 2011). Recent developments towards more formal support and services result from a range of social transformations including a stronger presence of women in the professional sphere, smaller families, geographical distance between family members, and a higher valorisation of one's autonomy. Actually, most carers take on this new role while carrying on with their professional activity (Henz 2006; Crompton and Lyonette 2006; Bereccki-Gisof et al. 2008). An important literature has developed on the (reciprocal) implications of both responsibilities. Many studies highlight tensions and conflicts on the family side and a modification of the professional participation, stressing a gender gap (Arber and Ginn 1995; Crompton and LeFeuvre 2000; Sarkisian and Gerstel 2004; Cullen et al. 2008).

There are significant differences between countries on how they rely on informal care services mirroring a diversity of cultural attitudes about the family (Bettio and Plantega 2004). Nonetheless, family carers do still play a key role, sometimes not so much in providing hands on tasks but rather as manager, employer (of the informal carers) and partner in the care arrangement that might include various (non professional and professional) care providers (Pommer, Woittiez and Stevens 2007; Saraceno 2010). The coordination function appears as a central dimension of the carer's role towards an elderly parent (LeBihan and Martin 2009).

As care regimes are concerned, a distinction between central and northern Europe, on the one hand, and southern Europe, on the other hand (Esping-Andersen 1990; Anttonen and Sipilä 1996) is generally agreed upon. The former are characterised by a well developed welfare state (only recently in decline) whereas the latter do not benefit from a strong welfare state and the offer in terms of services is not as extensive. We focus now on Southern European countries.

#### *Southern Europe and the specificities of the Portuguese care system*

Southern European health care systems (Greece, Italy, Spain, and Portugal) are characterised by strong family obligations, supported familialism and a model of a migrant worker employed by the family (Bettio and Plantega 2004; Bettio, Simonazzi and Villa 2006; DaRoit and Naldini 2010). However, in spite of its cohesion, the family alone cannot deal with the whole caring task. Thus various solutions are being developed by also including external services. However, if the expansion of home care services might

relieve families from part of their caring tasks, the development of nursing homes seems to have little impact, probably since for most families it is still considered as the least desirable solution, one which should only come into play once all other options have been explored to their limits. Hence, this solution tends to be delayed as long as possible (Haber Kern and Szydlik 2010).

In other words, the Southern European care model evolved from an unsupported familialism, with the obligation for families to care for their parents, without any support from the State, to a situation of familialism as an option or supported familialism (Leitner 2003). In some countries, families also benefit from some cash-for-care allowances stressing a “semi-formal” solution (Pfau-Effinger 2005). This is the case of Italy, where the cash-for-care is sufficiently high to allow for the integration of a migrant employee in most families (DaRoit 2007).

Portugal has an atypical profile, with commonalities and particularities in relation to the other southern European countries. Portugal is considered as a borderline case among southern countries where care is delegated almost entirely to the family (Bettio and Plantega 2004; Bettio, Simonazzi and Villa 2006; Wall and Escobedo 2010). Portugal is characterised by a strong commitment to family and more family-centred living arrangements and obligations (Wall 2005, cited by Wall and Nunes 2010). In fact, family obligations are undoubtedly strong as 87 percent of Portuguese believe that “children have to care for their parents at home” (Torres 2006). Portugal is also characterised by a high level of female employment (one of the highest in Europe: 65.6 percent of the 15-64 in 2010; Greece 59.6 percent; Spain 58.6 percent and Italy 56.9 percent (Eurostat 2010)). Working full time is the rule for both men and women across different social classes and a model of dual earner couples prevails (Wall 2007). On the other hand, retirement age is high (65 for men and women), so we can expect carers to be working and caring at the same time. And last but not least there is an increasing ageing population; in 2009, the 65+ represented 17.9 percent of the total population.

In Portugal the care system towards the elderly changed significantly during the last decades. From a system centred almost exclusively on family care it evolved into a more mixed model combining family, home help solutions, and day care centres. The access to publicly subsidized services is universal but depends on means testing; thus only very low income families (below the minimum national wage: 485 Euros in 2011) are entitled to free services, everyone else pays according to one’s income. But even if payment is



low, it may represent an important amount for the elderly person, especially if there is nobody (adult children) to help pay it. The rights and economical support for the carers in terms of leave policies and public subsidizing have also increased in terms of low cash-for-care and an annual 15-days leave. In Portugal co-residence of various generations is still socially accepted and valued and thus it is not rare to have frail elderly living in with their adult children. In some cases living-in care workers are also a solution, but it is rather rare in contrast with the Italian “migrant in the family” care model and only affordable for people with a higher income (Wall and Nunes 2010). The role of the family for elderly dependent persons thus remains essential. It goes hand in hand with the still central idea that the possibility to remain in one’s own home is the best solution for the elderly person. Economical reasons can partially account for this phenomenon. In sum, Portugal appears to be in transition from a still present strong familialism toward a more diversified and specific mixed model in which care services have been developed through strong publicly subsidizing of the third sector (Wall and Escobedo 2010). After considering work/care system in general and specifically in Portugal, we turn now to AD and its specificities.

*From the situation of chronic diseases to the specificities of AD*

Chronic diseases, characterized by the duration and uncertainty of the development, as well as the lack of treatment (Adam and Herzlich 1994; Kleinman 2000; Williams 2000) are particularly intrusive in the lives of ill persons and their families and may cause significant upheaval, « *the handicap of chronic illness may fall as heavily on the family as on the patient, in terms of problems created for daily living and family life, and through the search by the family for adequate responses to these problems* » (Anderson and Bury 1988: 7-8). The experience of such illness alters the individual’s biography and induces feelings of fear, anxiety, bewilderment, uncertainty and loss. The disease cannot be considered as an episode in life since it can last months or years, for as long as the person lives (Baszanger 1986); it is a situation that the person must endure, and adapt to, in family, social and professional life, in order to live with the disease. To care for a person suffering from a chronic disease has both a practical and an affective dimension. If this is common to all chronic diseases, AD specific characteristics, mostly constraining, amplify the intensity of the carers’ commitment. In a situation of chronic disease, the carer and the cared-for are engaged in a negotiation and co-construction of the situation; both are put to the test due to the modifications of communication linked to AD. The care

role is shaped through negotiations between the helped person and the one who helps, an interaction (Corbin 1992) to find a compromise between respective needs and the existing solutions. But with AD this negotiation is questioned or even inexistent, as the ill person disappears as an interlocutor able to negotiate, with tremendous consequences for carers and their relationship with the ill person.

Since AD interferes with all routines, daily references as well as the relationship to the adult children caring for a parent suffering from AD have to develop and learn new competences in order to manage the situation. They also have to invent or create new routines, models of communication and interaction as well as new kinds of relationships - both inside the family and with the outside world, including their sphere of professional activity.

Adult children caring for their parent suffering from AD not only have to face problems linked to symptom management (depression, aggressiveness) and daily living (to dress the ill person, to find him/her some activities) but also have to manage certain fears and apprehensions, emotions and personal needs. Care is therefore double faced: a physical accompaniment of the person, on the one hand, and a psychological accompaniment, on the other, bound to the comprehension of the disease. This daily learning process mobilizes various skills such as attention and patience, availability and time, but also ruse and ingeniousness. Furthermore, carers have to learn how to decipher the ill person's reactions and behaviour, to anticipate and respond to them, which requires unique communication skills.

The daily observations as well as previous more or less successful experiences constitute the knowledge upon which the experience of carers rests. The unpredictable character of AD, regarding its evolution, its manifestations, as well as the frequent changes it involves has a major impact on the experience of caring. Unpredictability is bound to uncertainty, shaping the relatives' reactions toward their new role for which they are not prepared. Changes in personality which develop with time complicate the caring and can be quite difficult to deal with for the adult children. Nevertheless, positive changes may occur, even if they are less frequent. The reconstruction work of the ill person by carers allows to figure out the modifications of his/her behaviour and to apprehend his/her progressive loss of communication (verbal at least). However limits exist in providing care; if responsibility assumed by carers is global, it does not become therefore total. Indeed, as dependence progresses, care extends to all daily activities. Nevertheless, it doesn't

suggest that carers do everything for and in the place of the ill person, since a partial autonomy can be maintained. Therefore the issue is to find, in a process of negotiation, a compromise which allows the relative to take care of the ill person while remaining attentive to themselves, by maintaining activities and preserving moments of rest. In other words, to take up the challenge, carers should not give up their daily activities, while not betraying the ill person. This implies training in order to become familiar with and adapt to the new situation.

Consequently, negotiations linked to the choices and decisions concerning the ill person are devolved upon the relatives. Those are based on their former knowledge of the person, on discussions prior to the diagnosis, but also on their own observation as well as on the ill person's remarks and reactions which are important hints to orientate their intervention.

Carers proceed to a reconstruction exercise of what the ill person likes or dislikes, of what they ought to do, what to say and how to handle at best for her/him. The issue is not only to remain in touch with one's ill parent, but also to take what the carer supposes to be the "best" decision for the ill person (Samitca 2006; 2008). Thus, while being continuously challenged by the disease, the knowledge that carers have of their parent constitutes a central element of care.

We present next the design of the study as well as the sample group and then we will discuss the main findings in terms of the care experience of family carers.

## **Methods and data**

In order to address the question of care arrangement for persons suffering from AD, we draw on the qualitative study we carried out in 2009 in Portugal.

### *Sample description*

This study draws upon qualitative interviews with adult children caring for an elderly parent suffering from AD. These adult children are the main carers providing hands on tasks and/or are responsible for the organization and management of the care arrangement.

We intended to interview both female and male carers but the latter were difficult to find. Our final sample (Table 1) consists of 13 adult children - 12 women and one man. Aged between 39-64 years (mean: 52 years), ten of them still have a professional activity. Five

of them also have children under 15 at home. Despite the small size of the sample, we managed to secure some diversity regarding the professional and socio-cultural background of the carers. Six have a university degree and the others completed compulsory school. Five hold highly qualified jobs such as university professors, managers, high school teachers, seven have professions such as aesthetician, language teachers, administrative personnel, and one housewife. With the exception of three of them (already retired, but still working in the first stages of the parent's disease), all respondents work full time. Their profiles income' wise are also diverse: six respondents have a high household income (between 3'000-5'000 Euros and more); five of them an average income (between 1'500-3'000 Euros) and two have a low household income (between 800-1'500 Euros)<sup>i</sup>.

The elderly parents – ten mothers and three fathers - are aged between 74 and 92. Five still live in a couple and five also live in co-residence with the adult children. The cared-for persons have middle-high to high levels of dependency; a few of them still have some autonomy, while others need constant help or are even bedridden. Regarding the cared-for persons' income the sample includes five low pensions (under 1000 Euros), four average pensions (up to 1500 Euros) and three high pensions (1500-3000 Euros). For one cared-for person this information was not provided. All respondents, as well as the cared-for persons, live in an urban area, in a major city.

The sampling was completed by convenience, snow-ball and purposive sampling (Patton 1990)<sup>ii</sup>. Although the qualitative research is based on 13 interviews, we rapidly reached a state of saturation of information which allows for some significant generalization to be drawn from this exploratory study.

All the interviews were taped and transcribed integrally. After each situation was analysed in depth through content analysis and we then engaged a transversal analysis of the main themes and issues, taking stock of the specific context of Portugal. In detail, we aimed to investigate the main care arrangements set up by families, as well as how adult children managed to face work and care. From what form of support did they benefit? What was the most difficult for them? Did they benefit from some support, and of what kind?

*Insert Table 1- Characteristics of the sample*

## Main findings

In this section we see how carers set up care arrangements and their different types; the reconciliation between work and care as well as the care implications for the carers.

### *Setting up the care arrangement*

Concluding a period of perplexity and uncertainty, the AD diagnosis forces the family into a redefinition of roles and activities. The first challenge is to define who will care for the parent. To care for one's elderly frail parent is mainly considered a family responsibility that respondents feel "normal" and agree to fulfil (Finch and Mason 1990; Matthews and Rosner 1998; Guberman et al. 2006; Connidis and Kemp 2008; Funk 2010; Stuifbergen et al. 2010). Concurrently, nursing homes still drive negative images and therefore are considered as the ultimate solution.

In our sample, as mentioned in the literature, care is organized around one person – the main carer – with the help and support from other family members and/or formal services. The process through which one becomes a carer is not a proper negotiation between siblings. It is rather the decision or conviction of one family member – often one of the adult children – that the parent should be cared at home. Then an arrangement is set up, most of the time resulting in one person becoming responsible for the organization of care as well as for the communication with the others and their involvement in the discussions and decisions. This does not always result in a shared care arrangement, but rather in situations mirroring to different levels of "togetherness": from a situation where one did everything but kept the other(s) informed, to situations of shared caring by turns. Most of the time, the other siblings are more ready to visit the elderly parent and are available when necessary, i.e. when the main carer is absent or when he/she needs some help. But it is mainly on request. The success of this kind of arrangement is variable.

**Joana**<sup>iii</sup> *"According to my brothers she would already be somewhere (nursing home). I am the one who said no. I said no because it is something she doesn't want [was there a negotiation?]. Oh no, I gave my opinion, I think it is too early (...). I didn't negotiate anything, I gave my opinion and they agreed."*

*(...) the others do more visits ... for the medical consultations we try to go together with my sister since she is linked to the health field (...).The two*

*other brothers are present only when it is really necessary (...) Of course if she [her mother] asks or if I say you have to go there or when she is more down, then they go, they wouldn't fail. But for the day-to-day it is different"*

**Rita** *"In fact what happened is that I took a little bit the leadership; it had to be (...) My husband didn't agree [with one of Rita's decision], neither my brother did really agree, I mean the youngest, because the other, well, he is further away and was always more distant from the situation (...). Yes I think that in-between the limitations he had [the brother] ... we talked a lot about it and now he gives a little help as he wants to. I also thought it wasn't the point... we reached a point it wasn't useful to argue more about it".*

It also happens that in spite of having siblings, for various reasons, the main carer is the only one to take part in the care arrangement. From the interviews it is clear that families cared for their parent because they want to do it; they think either that it is a duty or something "natural", according to various social relationships, mentioning among other things reciprocity, "My parents cared for me, now it is my turn to care for them".

Interestingly, if respondents (most born in the 1940) are committed to the care arrangement for their parent, they insist on the fact that they do not want to require this from their own children due to the sacrifice it implies. Some respondents have even already organized a care solution for their (future) old days. Moreover, although this family obligation is still strongly consensual, almost all respondents insist on their expectations towards the State for more help. They lament a lack of acknowledgment of their personal investment, too often taken for granted, and consequently a lack of State support for carers (financial, services, allowances).

#### *Division of tasks*

The division of tasks can be understood by two main factors: gender and the professional background. As already well identified in the literature daughter(s) are usually the main carers, keener to engage in hands-on tasks and/or watch over care; whilst sons are keener to visit their parent (Bocquet 1994 ; Clément 1996; Haberkern and Szydlick 2010). Thus, the responsibility of managing and organising the care arrangement as well as of checking that the ill parent is well cared-for was most often taken on by one daughter. It seems that in many families the division of tasks between siblings can also be linked to their professional activities, i.e. if a brother is a doctor he will be responsible for the

contacts with doctors or if the daughter works in the financial field she will manage all the economical aspects of care.

An interesting situation to consider is the one of Vanessa who takes on the care arrangement of her mother together with her sister and brother (she has two brothers but one didn't take part in the care arrangement). They have a non-professional paid carer who stays with their mother during the week and then at weekends they care for their mother, in turns. Vanessa, the respondent, estimates that it is more difficult for her brother to deal with the situation and to reconcile caring for his mother and his own family.

**Vanessa** *“There was little negotiation. It is a heavy burden and we don't know how things will develop so we have to share between us (...). There are indeed some slight divergences between us but we agree that we will keep our mother at home as long as she recognizes her house, independently of the difficulty it could represent for us and that we will make an effort in order to make this happen. There were some divergences; in fact my brother was really in favor of putting our mother in a nursing home (...) I personally always disagreed with this solution”.*

The responsibility of the care arrangement is divided between siblings, with some specific tasks for each one and also arrangements by turns (one weekend each one); however each one can then manage his/her turn as he/she wants, according to his/her preferences and family life. Besides, the way the situation is experienced is also very different from one adult child to the other, according to his/her own life and family context. For instance, when it is the respondent's brother's turn, he hires somebody to stay at home with his mother. Some respondents mention the lack of expected help and support from one sibling. Those respondents neither understand nor agree with their siblings' attitude, but nevertheless accept it rather than “fighting” against and adding more stress to an already stressful and anxious situation. They feel sorry that the siblings do not get more involved but at the same time they do not want to complain and prefer to avoid any situation of potential conflict. Maybe as a result of tiredness they give up expecting something and simply try to cope with the situation.

#### *Caring arrangements in practice*

In this section we review the empirical strategies of the carers. Which are the care arrangements set up and how do they fit in with the carers' caring ideals, values and

expectations. Although the life stories are very different, carers' trajectories or experiences show important similarities. When considering the care arrangement, it is important to take into account both its composition and the intensity of the care/services provided, whether this is done on an occasional or extensive basis. Families may rely on a range of services and facilities in order to cope with the caring situation at home. It is thus also essential to identify the various resources mobilised by the family.

Drawing on the interviews, we can describe two main types of care arrangements, a family pattern and a mixed one:

- In half of the situations, care is informal, provided exclusively by family members. It involves the main carer (respondent) alone or together with other family members, i.e. the cared-for person's spouse, other adult children or, as well, carer's children. Except in one situation, this is possible thanks to the presence of the cared-for person's spouse who takes on a watching-over role.

- In the other cases, informal care and paid formal care are complementary. Formal paid care is provided by non-professional carers such as a house-employee or a home-helper, private, or provided by the Alzheimer association (APFADA) - who stays at home with the cared-for person. This non-professional sometimes benefits from a short training from the APFADA focusing on how to care for a person with AD. In many situations the APFADA is present and provides support, mainly for personal hygiene and through physiotherapy services. Public subsidized professional services also provide help and support; the most used ones are day-care centres, home care services for physiotherapy or meals on wheels.

In situations in which the cared-for person is in an advanced state of illness or was bedridden, complex mixed care arrangements combining family and other types of care are more frequent. In this case, care patterns include various carers, i.e. somebody during day-time, another one at night and a third one for weekends; all of them are paid. This is the case of Marta, who cares for her mother. During week days, while she works, her house employee stays at home with her mother the whole day long; at night she has private paid help to put her mother to bed, plus a person for hygiene tasks during week days and another one on Saturdays. In such advanced state of the disease, carers insist on providing their parent with cuddle and comfort. It is thus not so much hands-on tasks – often delegated to professionals – that are at stake but rather the behavioural modifications or the loss of the communication which have heavy emotional



consequences for the carers. Contrarily to what we could have expected, when the person is in an advanced phase of the disease, needing always more and constant presence, often carers find this stage less constraining and easier at a more emotional level since the person does not wander of and stays calmly at home (Martin et al. 2009).

Although the two types of care arrangements are equally represented, combining informal and formal care is the strategy mostly chosen by families (Samitca and Wall 2008; LeBihan and Martin 2009). Arrangements may vary considerably and depend on several shaping factors such as the elderly person's needs and wishes, the participation of another carer i.e. the elderly person's partner even if only on a "watching over" capacity, the families' level of income and ability to buy in certain types of services.

To care for a parent suffering from AD is highly demanding. Some respondents feel they have reached their personal and emotional limits and cannot face the situation anymore. Therefore, they consider the possibility of putting their parent in a nursing home. This situation isn't easy because persons suffering from AD are not always accepted in nursing homes; besides high quality nursing homes are very expensive and few could afford it. Some parents had expressed their disagreement with this solution a long time ago, generally before becoming ill and thus carers try to respect their parent's wish. In fact, most respondents prefer to have somebody at home either to ensure the constant presence requested by the cared-for person and/or to provide caring tasks, e.g. hygiene. But in this scenario, the financial dimension often constitutes an obstacle.

With no exception, respondents explain how hard and challenging the caring situation is and how in order to deal with it, help and support are required. Respondents consider that care for an elderly parent should be provided first by families but with a substantial support from the State, although not the case at present. Respondents expect the State to supply more facilities and services for family carers, as first or main care providers, in order to help them facing both the caring and working tasks. The support of the State should include health care provision, cash-for-care and more flexibility from the professional sphere (Samitca and Wall 2008). An annual 15 days leave is extremely short when caring from a parent suffering from AD.

Globally respondents are satisfied with the care arrangement and stress the quality of work of the paid carers. They all insist on their human qualities and skills to care for their parent suffering from AD, describing them as very kind, patient, understandable, and with some competences for dealing with the specificities of AD, although most of them

do not have much training, some of them got a short training from the APFADA on how to be with AD persons.

Respondents stress also the fragile and short-lived character of the arrangement, they are well aware that the situation might change suddenly and rapidly, for the worse, and they will have to adjust the care arrangement. The necessity to adjust continually and perpetually is characteristic of caring for a person suffering from AD.

### *Reconciling work and care*

Regarding their professional activity, respondents do not mention significant repercussions. When they exist they are above all associated with a loss of concentration and organization, or to the necessity to juggle both responsibilities and schedules. Only one person gave up her professional activity in order to care for her parent.

Although working and caring at the same time is a source of stress in terms of conciliation (Samitca and Wall 2008), it can also be - and often is - a source of support. Work has in fact a “buffer effect”. It provides respondents with a refuge from the constraints and preoccupations of caring. Respondents are not only reluctant to the idea of quitting their job, but they also stress that it helped them. Moreover, they cannot imagine caring full time or being full time with their parent.

**Rita** “... full time [at home] would be impossible, I couldn't. It is perfect if some people manage to do it, I couldn't (...) I think they should always be somebody to help, even a home-helper who comes and gives tips and helps. I think that alone it is unthinkable, it is too much”.

**Vanessa** “My situation is completely different from that of a person who would care the all day and every day. It is completely different and I am not sure I could do it. I would have difficulties. I think that if I had to deal everyday with such situation and care every day, I would have difficulties in organizing my life”.

Work even allows some room for leisure time. One respondent manages to meet friends or have time for herself by taking half day or one day off during the week. She can enjoy the situation without worries, since the care arrangement is stable. On the contrary, it is more difficult to plan something outside on weekends since she is the person responsible for caring.

In the same way, a respondent took an early retirement before her parent's illness and regrets it now. When working she had more freedom and could arrange time for herself. With this caring arrangement she feels almost locked up at home with her mother, a difficult situation since she retired in order to make the most of her life and not in order to care.

Respondents insist on the importance of their professional activity not only from a financial point of view, which of course is important, but mostly from the perspective of one's personal fulfilment and satisfaction. In spite of the stress it implies, professional activity helps carers to face the situation. This issue is extremely important when thinking about which of support to put in place in order to help the carers.

**Rita** *"[To quit my job] this you can forget (...). I cannot leave my work because I am not a person who could work with elderly persons. (...) When the person works she manages, she is involved in what she is doing ... and it even helps a lot".*

**Vanessa** *"Honestly I think that I succeeded in managing it. I think my situation is completely different from the one of a person who should care 24h per days every single day (...). I don't know if would be able to do it, I think I would have some difficulties".*

Respondents make few references to any support they have received from the work place. However according to other similar studies the most significant support is when carers benefit from some sort of negotiation at their work place, as well as the understanding from their employers and colleagues (Samitca and Wall 2008).

#### *The implications for the carers*

Providing care for one parent suffering from AD has considerable consequences on the carers' life, at family and social levels, as well as at emotional and economical levels, as we will see now.

At family level, the most frequent repercussion expressed was a lack of time: for oneself, for the children and also for personal activities and leisure time. A narrowing of freedom is also often mentioned, associated to a loss of spontaneity. In other words from now on, everything has to be planned and organised. For most carers the situation interferes with their life drastically. Some carers even feel trapped in the situation, having lost the possibility to have their own life and to organise themselves. Part of the respondents feels

as if they cannot escape from the situation and are left without any autonomy. Such situations often induce negative feelings and could increase the difficulties to deal with the situation. Nevertheless, some respondents spend a lot of energy attempting to maintain some social activities and free time for themselves.

At social level, the key word is “renunciation”. Almost all respondents mention that they had to give up numerous activities (leisure, holidays ...) not only due to a lack of time, but also and mostly due to a lack of mental receptiveness. Everything must be thought of taking into account the cared-for person, and the organisation of the carer’s life (where to go and when, what to do, ...) depends on the cared-for person. Whether living in with the cared-for parent or not and in this latter case even knowing that the person has some help, carers cannot avoid taking into account their parent’s situation and needs when planning something.

**Beatriz** “... our life nowadays is thought according to them (her parents). (...) of course it has been a tremendous change (...). Now it seems that I am the mother and she is the daughter. Sometimes, I am more tired; sometimes I am not so patient for those daily situations.”

“In fact it is frightening when the person loses the notion of who he/she is and of who is and always lived next to him/her and suddenly the person doesn’t recognize anybody”.

To juggle various activities also constitutes an obstacle to the realisation of some personal and social activities, often ending in giving them up, due to the anticipation of the associated difficulties or implications in terms of organization (cost, tiredness, worries ...).

At the emotional level, feelings of sadness, intensive worries, distress and anxiousness, as well as frustration and loneliness are frequently mentioned. Even if the organizational aspects are demanding and burdensome, the most devastating and difficult to cope with is the emotional component of AD. To witness the transformation of personality of the loved person is extremely distressing. Routines and habits change and, at a more advanced level of the disease, it can happen that the cared-for person does not even recognize her/his family. Thus, both cared-for person and carer become “strangers” to each other. Caring for a parent suffering from AD is an unending and overwhelming situation. One of the most detrimental aspects is to be constantly on call and worried. One respondent mentions the sacrifice that represents caring for one parent with AD and

another stresses the destructive dimension of the illness for the carers “*the illness is devastating; family remains exhausted, devastated and discouraged*” (Fernanda).

**Joana** “*we can also choose to have a person full time at home, however... I don't know why but those ill persons are exhausting, they tire everyone out until the person who stays and cares for them doesn't have any patience left*”.

Respondents are well aware of the importance of their own activities and how it can be a support for themselves to maintain their social life or at least part of their activities. Some even mention as a motto, “life goes on”, “one cannot stop”. Some of them however admit that it is sometimes easier to say so than to realise it, since it induces constraints and implies a lot of organisation, planning and juggling. Moreover, energy and motivation to go out, to meet people are necessary but often lacking, as a consequence of caring. Carers feel exhausted and the hypothesis to go out, to have leisure activities seems too demanding, even though they know it is important and that afterwards more often than not, they are pleased to have met people or to have been to the cinema.

At the financial level, we must emphasize that AD involves consistent costs, especially for medicine and other care “accessories” such as nappies, anti-bedsore cream, etc, as well as for services. When considering the repercussions we should not minimize the fact that with AD, one must always expect that the situation might and certainly will worsen.

## **Conclusion**

In this paper we reviewed the situation of families caring for an elderly parent suffering from Alzheimer's disease (AD). Although social visibility is still scarce and the disease itself is fear inspiring, AD affects a growing number of persons, mainly among the 65-years-old and over. The impact of the disease and its caring needs go beyond the person's illness itself to encompass the whole family and social life. Consequently the question of who will care for persons suffering from AD is of key importance and is a challenge for future health and social policies.

From our study we can highlight four main conclusions: First, as care arrangements are concerned we find that adult children providing care for a parent suffering from AD face a very complex shift into the role of carers; there is no blue point. They must care in face of major changes and loss of reference. In sum, they must redefine their relationship with their ill parent. AD is a highly demanding situation for a carer, not only because the ill

person requires a lot of care, support and a constant presence, but above all because to witness the transformation of one's parent is a disconcerting and confusing experience.

As daily routines and habits are put into question and communication alters, main carers have to deal with a demanding and burdensome situation. Given the drawn out process of Alzheimer, care has to be adapted slowly and continually over the years. If a person alone can assume this task at the beginning of the disease, quickly all carers refer to a need of greater support. As a consequence a variety of care arrangements emerge. They draw on available family support (mostly with a gender division of tasks) or on mixed arrangements that imply a wide range of services. This period of mixed care can last for many years. AD initial caring needs and difficulties are very high just like in the advanced stage for other diseases. Thus it is crucial to better understand how families deal with the situation and manage their new carer's role, identify and use the available support.

Secondly, concerning the work/care balance, we have shown how fully employed people who simultaneously care for a frail elderly parent try to keep them at home as long as possible. Thus the issue of reconciling work and care is central and often a source of strain and tensions. Carers are concerned by their personal and family life, which suffers the impact of the elderly parent's disease. Often they have no choice but to give up some activities, mainly leisure and free time. The carers we met insist however on the key role of their professional activity that is barely affected by the situation. Indeed, working seems to have a positive impact on the carers' situation. Although working and caring at the same time is a source of stress in terms of schedules management and stress, work has a buffer effect. Paid work appears as a significant and key support tool that helps carers face the demanding situation of caring. In fact, respondents refer to paid work as a source of gratification. Sometimes it is also the only time or activity that the carer has for him/herself. As such, professional activity also provides a social network and contacts. Work is experienced as a source of respite; it offers a break from the constraints of the caring situation, as well as a sense of balance. Work helps carers find and maintain equilibrium and helps to cope with the emotionally heavy task of caring for a parent suffering from AD.

Thirdly, in Portugal there is a mixed scenario of continuity and changes. Although family care is still central, it is complementary to paid care (professional or not) combining various home based solutions. In Portugal carers rely upon increasingly mixed and

diversified models of care, including both paid and non paid, institutional and home care where family still has a pivotal role, complementary to the other forms of services and care. However, in the case of AD, this resource is limited since there are very little services and health facilities addressed specifically to persons suffering from AD and their relatives.

This brings us to our fourth and last conclusion referring to the implications associated to the needs of the carers from a policy perspective. Since the needs in terms of care are increasing, it is urgent to think about innovative forms of support, services provision and availability of proper facilities in order to offer good quality care to the elderly persons suffering from AD. This would also support carers maintain their professional activity. In sum, additional investment is needed to improve the offer and the accessibility of affordable professional solutions specifically addressing families with a parent suffering from AD.

Table 1- *Characteristics of the sample*

<b>Interview (sex /age)</b>	<b>Married/ living together</b>	<b>Children (living at home)</b>	<b>Sibling (sisters)</b>	<b>Level of education</b>	<b>Job</b>	<b>Cared for person (age)</b>	<b>Care needs</b>	<b>Live with dep pers</b>	<b>Care arrangement (family members)</b>
Gonçalo (M, 53)	Yes	1	2	University	University professor/ Researcher	Father (81)	High  24/24	No	Family  (cared-for person's partner)
Beatriz (F, 48)	Yes	1 (1)	1 (1)	University	English teacher (high school) + member of the college direction	Mother (77)	Middle  Needs orientation	Yes	Family  (cared-for person's spouse and respondent's husband)
Sonia (F, 51)	Yes	2		Compulsory	Volunteer work	Mother-in-law (76)	Middle	No	Family  (cared-for person's spouse)
Angela (F, 50)	No	0	1	University	Language teacher Quitted to care for her mother	Mother (87)	Middle	Yes	Family
Matilde (F, 58)	Yes	1	1	Compulsory	Language teacher  (adults, foreigners)	Mother (76)	Middle	No	Family  (cared-for person's spouse)
Rita (F, 51)	Yes	2	2	University	Language teacher  (high school)	Father (77)	High  Constant watch over	No	Mixed  (respondent's brothers and sisters)



									Nursing home since five months
Vanessa (F, 46)	Yes	2 (2)	3 (1)	University	Marketing (multinational company)	Mother (80)	Middle	No	Mixed (respondent's brothers and sisters)
									Non professional paid care at home
Joana (F, 48)	Yes	3 (3)	3 (1)	Compulsory	Works in a bank	Mother (75)	Middle/high	No	Mixed (respondent's brothers and sisters)
									Day care centre
Luisa (F, 39)	Yes	2 (2)	0	University	High school teacher	Father (74)	High	No	Mixed
							24/24	Lives next door	(cared-for person's spouse)
Graça (F, 64)	Yes	3	1†	Compulsory	Retired Civil servant	Mother (89)	High	Yes	Mixed
							24/24		Non professional paid care at home
Fernanda (F, 48)	Yes	1 (1)	0	Compulsory	Aesthetician	Mother (80)	High	No (works next door to her parents)	Mixed (cared-for person's spouse)
							Bedridden		Non professional paid care at home
									Nurse

Marta (F, 60)	No	0	2(2)	Compulsory	Civil servant	Mother (92)	High 24/24	Yes	Mixed (respondent's sister) House employee Physiotherapist Non professional paid care at home
Sofia (F, 58)	Yes	2	1	Compulsory	Retired Human sources direction	Mother (91)	High Bedridden	Yes	Mixed House employee

Dependence level: *High*, when the elderly person needs constant presence and help for almost all daily activities, some of them are bedridden. ), *Middle* When the person still has some autonomy and needs help for some daily activities (hygiene, dress oneself, cooking ...)

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<sup>i</sup> The above mentioned incomes are household income when both partners work. When the carer is alone the income means considered are respectively High = 1'500-2'000 Euros, Average = 750-1'500 Euros and Low = 400 or less-750 Euros.

<sup>ii</sup> For the latter, I mainly thank the Portuguese Association for Families with Alzheimer's disease APFADA). However, the sample only includes some APFADA's members, since the aim wasn't to study the Association and its members. Moreover only a minority of families concerned by the disease attend the Association.

<sup>iii</sup> In order to respect the privacy of the person interviewed, all the names have been changed