

Facing Costs With Dementia: Daily Lives Perspectives From Informal Caregivers

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Abstract

Background: Caregivers of people with dementia report stress, depression and economic burden compared to other caregivers. This study aimed to characterize the daily lives experiences of dementia patients' informal caregivers and to uncover day-to-day sources of expenses related with dementia care.

Research design and methods: Qualitative observational study, following a grounded theory approach. Data were collected with semi-structured focus groups with informal caregivers of persons with dementia. Discussed themes included changes in daily lives, formal care services utilization, quality of life and costs. Content analysis was conducted with Charmaz's line-by-line open coding procedure.

Results: Overall, 14 relatives of persons with dementia were included. Most of participants were female (12) and eight of them were daughters of the patient. Ages ranged from 39 to 84 years and eight had a high degree of education. Four of the caregivers were professionally active and the range of years assuming the role of main informal caregiver varied from two to 15 years.

Conclusions: Findings provide insight into the daily life experience of caring for a person with dementia, while revealing the impact on the quality of life of caregivers. The individual sociodemographic and psychosocial characteristics, together with a lack of adapted formal care services and low financial aid led to a high burden experience for these caregivers. A multidirectional approach addressing caregivers needs, while improving formal care services and creating social and financial support programmes for families affected by dementia is required to decrease its financial and psychosocial burden.

Introduction

As population longevity increases, so does the prevalence of dementia conditions, with still no effective treatment for this type of neurological diseases. In Europe, the number of people with dementia is expected to increase up to 14 million by 2029 [1]. Dementia is a clinical syndrome characterized by impairment in language, memory and other cognitive functions, with significant changes in patient's behaviours and high dependence to perform activities of daily living [2, 3].

Dementia causes disability and dependency, often associated with stigmatization, barriers to accurate diagnosis and access to formal care services. These difficulties in formal follow-up of dementia patients create high physical, psychological and economic impact on family caregivers and societies worldwide [4].

Over time, being cared on a daily routine by family caregivers becomes particularly important before institutionalization of people with dementia. Indeed, as patients dependency for daily life activities diminishes, the number of hours dedicated to the patient by informal caregivers increases more and more [5–7]. A recent study find out that the mean of hours per month of informal care of individuals with dementia was significantly higher when compared to formal care [8]. Informal care is a substitute for

formal care services when a certain degree of dementia severity is reached. At some point, health support becomes harder to be provided by the family, and institutionalization is commonly considered [9].

However, taking care of a person with dementia can entail pervasive costs. A study of Wimo et al., 2013, reveals that depending on country and AD severity group, 60% of total societal costs were supported by informal caregivers [10]. There is not only a financial burden, but also a physical and emotional due to the demanding responsibilities and time expenditure that are required to supporting basic activities and supervising the patient [11–15]. According to Alzheimer's Disease International, half of the dementia patients' caregivers tend to experience health problems, 49% modify their professional life and 62% have their social life seriously affected because of the caring obligations [16]. Additionally, emotions involved in caregiving (such as guilt, resentment and loneliness) are often very difficult to cope with by informal caregivers. On the other hand, caregivers can experience positive feelings about their caring role and find opportunities to enhance their familiar relationship after dementia diagnosis [17].

Since caregiving varies from case to case, some studies discuss how sociodemographic factors (such as gender and age of caregivers), as well the nature of relationships with the care recipient, affect the caregiving role [6, 18, 19]. Few qualitative studies have collected the perspectives of family caregivers about the access and quality of formal care services and about informal caregivers' daily needs and difficulties related to the care of their relatives suffering from dementia [20–23].

Published studies from Portugal or including Portuguese data focus mainly on the perspective of formal caregivers and do not allow a good and detailed characterization of the Portuguese context of dementia informal caregiving [24–26]. Currently, there is a worldwide lack of knowledge, awareness, and an in-depth understanding of dementia impact on caregiver's daily life. Results from a recent review have shown that the negative aspects involved in informal caregiving prevail over positive, to caregivers, and that the high complexity of the experience of caring can only be reduced with multidirectional approach addressing these community's needs and improving the quality of life of the person with dementia and their family caregivers [27].

Given the paucity of studies sought to understand the global experience of caring for a person with dementia, a qualitative study addressing the characterization of the perspectives of Portuguese informal caregivers about what it takes, in daily life, to care of a relative with dementia is lacking. A focus on the costs related to dementia is of particular importance to describe the perceived effects of the task of caring through caregivers' voices.

In this study, we aimed to contribute to the understanding of the informal caregiving role and its impact on caregiver's daily life's, while describing the use of financial resources and the dementia-related costs. The caregiver's views on what is necessary to improve not only to promote better care for the affected relative, but also to promote caregivers' quality of life are of paramount importance to make informal caregiving as a positive life experience.

Methods

- **Design**

This study followed a qualitative observational design. A grounded theory approach was used, with the intention of development a conceptual characterization of the phenomenon under study (informal caregivers' experiences with relatives suffering from dementia, with a special focus on costs and needs), with no *a-priori* theoretical backgrounds. Grounded theory designs constitute an adequate methodological approach for this data-driven conceptualization effort because it uses the empirical (collected) data to generate concepts and theories, through a constant data-comparison process [28–32].

Data collection was done using semi-structured face-to-face focus groups, with constitute a form of group interview that promotes interaction and encourages focused communication between the moderator (i.e., the researcher/s) and participants. This is an adequate method for promoting participants to ask questions to each other, and to spontaneously exchange personal experiences and opinions on a given subject [33, 34].

- **Focus groups composition and participants**

Focus groups were performed with Portuguese informal caregivers of person with dementia. The sessions were conducted with small groups, to give participants enough time to share experiences and perspectives. Informal caregivers were considered eligible for the study if they were adults taking care of a relative with dementia (formally diagnosed as having dementia or as possible/probably AD). The sample was constructed with the intention of covering a wide range of caregiving experiences. For this purpose, the focus groups composition were heterogeneous regarding the stage of the relative's disease (i.e., including, in each focus group, caregivers of relatives in early and in advanced stages), participants with different ages, different family relationships to the person with dementia (spouse, daughter,...) and different professional situations. We also sought to have caregivers taking care of dementia patients for different durations per day and for different moments of the day.

- **Sampling and recruitment process**

A non-probabilistic and purposive sampling approach was followed, with caregivers selected according to the inclusion and heterogeneity criteria described above. They were invited to participate from two different settings: upon a neurology appointment at the Centro Hospitalar Universitário Lisboa Norte E.P.E (reference university hospital for dementia) and following the presentation of the project at a nursing home, located in Lisboa, Portugal. Participants received oral/written information on the details of the study (goals and procedures) at an informal meeting, followed by dedicated information and the informed consent form. Before the beginning of the focus group, informed consents form was signed by each participant. Participants were also asked to provide some written background characterization info including basic demographic information and for how long they had been caring of their relatives.

- **Data collection**

An interview script was developed, according to four main topics: i) participants presentation, including a brief narrative about the onset process of each caregiver career (type of family relationship with the person suffering from dementia, for how long they had been caring their relatives); ii) living with dementia and main adaptations in caregivers “normal” routine; iii) experiences and concerns related to the personal and family’s financial impact of dementia; iv) expectations for improving the task of caring for a person with dementia, not only to promote better care for the affected relative, but also to promote caregivers’ quality of life (*see Additional file 1 of Supplementary material* for the interview script and questionnaires applied to the caregivers).

The focus groups were conducted by two experienced and trained researchers, one as moderator who fostered an active and open discussion, and the other as a co-moderator. A third researcher was also present to ensure written annotations (field notes) for each session. Focus groups took place between November 2019 and December 2019. Most part of focus groups took place at the Institute of Environmental Health of the Lisbon School of Medicine (ISAMB-FMUL); only one was conducted in a day center facility, located in Lisboa, Portugal.

- **Data analysis**

Focus groups were fully transcribed and the content analysis was performed MAXQDA 2020®. After a first reading of the corpus (composed by the transcriptions of all focus groups), which promoted an intuitive first set of analytical codes, the open coding evolved to a line-by-line type analysis [28]. The chosen unit of analysis was participants’ utterances (instead of each line), for each focus group, following a constant comparison process (between the whole corpus and each focus group section). This content analysis was done with two researchers, ensuring interpretation triangulation: one of the researchers who was involved in the content analysis has a background in dementia, the other has a background in psychology; both having training in qualitative research.

After completing the line-by-line content analysis, researchers examined the code system and similar concepts were collapsed into larger categories (axial coding). Finally, and taken also into account participants’ sociodemographic information, a conceptual model was created linking the categories that emerged from the analysis [28].

Reliability was ensured by following the procedures for grounded theory studies outlined by Strauss and Corbin [31]. Data were compared several times by the authors, providing a check for credibility. An executive summary was afterwards sent to the focus groups’ participants, who were invited to comment and provide additional insight to the main results and conclusions of the content analysis. Their feedback was also used for the elaboration of this paper.

- **Independent review board approval and consent to participate**

Ethical approval was obtained from the competent Ethics Committee (Centro Académico de Medicina de Lisboa - CAML) in October 2018. Participants were informed, verbally and through e-mail (or through mail, according to participants' preference), and the written consent form was signed. The participation was voluntary, and participants knew that they could withdraw at any time without any prejudice. To ensure participant's anonymity, a code number was assigned for each participant in the transcribed files and for matching between transcription contents and the short questionnaire with additional demographic data. Information having the potential to allow the identification of any participant was withdrawn from the transcripts. Demographic elements were only used as a context for interpretation the qualitative data and for describing (in an aggregated form) the involved sample.

Results

3.1 Description of the focus groups and participants

Fourteen caregivers attended the focus groups, in a total of four sessions. All participants were family members of person with dementia (nine have been diagnosed with dementia, and five were diagnosed with AD, the range of years since diagnosis varied between two to 15 years, 11 were woman, and the mean age was 81 years, varying from 70 to 92 years), (Table 1). Two of the Person with dementia being taken care of recently moved to a nursing home, one was benefiting from formal home care for personal hygiene (due to the difficulties of the caregiver in performing those tasks), seven visited a day center and four did not benefit from any formal care services (Table 1).

Of the fourteen caregivers, 12 were female, the mean age at the time of the participation in the focus group was 64 years old (range: 39 to 84 years old). Eight were daughters of the person with dementia, one daughter-in-law, two husbands, one wife and two sisters. Eight caregivers had a university degree, three completed high school and three completed primary school. Four of the caregivers are professionally engaged (3 full-time and 1 part-time), four were unemployed and six were retired. Ten caregivers have been caring for their relatives over five years, six participants reported to spend more than 10 hours a day in tasks related to informal care (Table 1). Twelve were the only caregivers for their relatives, while two had additional support from other family members. One of the included caregivers did not live with the relative (who still lived alone) but maintained a very close monitoring of daily activities. Regarding caregivers' own difficulties, eight admitted to have had personal problems within last 6-12 months (Table 1).

Table 1 - Background characteristics of participants (n=14) and their relatives with dementia					
Background characteristics		Number/ (%)	Background characteristics		Number/ (%)
Family caregiver (n=14)			(Person with dementia) (n=14)		
Age	Average age (years): 63.5		Age	Average age (years): 81.43	
	Range: 39-84			Range: 70-92	
Gender			Gender		
	Men	2 (14.3)		Men	3 (21.4)
	Women	12 (85.7)		Women	11 (78.6)
Highest educational attainment			Highest educational attainment		
	Did not complete any degree of study	0 (0)		Did not complete any degree of study	2 (14.3)
	Primary school	3 (21.4)		Primary school	6 (42.9)
	High school	3 (21.4)		High school	2 (14.3)
	University	8 (57.2)		University	4 (28.6)
Relationship with Person with dementia			Diagnosis		
	Daughter	8		Dementia	9 (64.3)
	Husband	2		Alzheimer's disease	5 (35.7)
	Sister	2	Years since diagnosis		
	Wife	1	Average (years): 6,14		
	Daughter-in-law	1	Range (years): 2-15		
Professional status			Std. Deviation (years): 3.505		
	Full time employee	3 (21.4)	Residence		
	Part-time employee	1 (7.1)		Person with dementia house	8
	Unemployed	4 (28.6)		Caregivers' house	4
	Retired	6 (42.9)		Nursing home	2
Time of care			Formal care services utilization		

1 to 2 years	1 (7.1)	Home care services (daily)	1
3 to 5 years	3 (21.4)	Day center (5-6h/day)	7
More than 5 years	10 (71.4)		
Daily hours of care (in the last 30 days)			
Less than 1 hour	2 (14.3)		
2 to 4 hours	1 (7.1)		
5 to 7 hours	3 (21.4)		
7 to 10 hours	2 (14.3)		
more than 10 hours	6 (42.9)		
Life problems in the last 6-12 months			
No	6 (42.9)		
Yes	8 (57.1)		
Does not specify the type of problem	1 (7.1)		
Death of a family member	2 (14.3)		
Health problems	4 (28.6)		
Several of the above	1 (7.1)		
<i>*Persons with dementia cared by their relatives, not included in focus group sessions</i>			

3.2 Themes emerging from the content analysis

From the content analysis, the main themes identified (most cited/most coded) included changes in quality of life of the caregiver, costs related to dementia and the formal care services received (Table 2). The category “Changes in quality of life” was the most frequently referred to, accounting for 396 segments (6.43% of the total corpus’ segments, all focus groups included), including: “Personal life”, with 152 segments (2.47%), “Caregivers’ health”, with 140 segments (2.27%) and “Emotional burden”, with 104 segments (1.69%). The code “Costs related to dementia” covered 215 segments (3.49% of the total corpus) and the code “Formal care services received/lack of formal care support” covered 207 segments (3.36% of the total corpus). In this paper, only these themes are discussed in a more detailed way. For

consulting the complete set of themes emerging from the content analysis, consider *Additional file 2 of Supplementary material*.

Table 2. Content analysis: categories, themes and sub-themes

Category	Theme	Sub-theme
<i>Quality of life</i> Changes that affect physical, mental, and social well-being leading to disease, stress, depression, low sense of dignity, social isolation and anything different that a healthy status Changes in caregiver's personal life	Caregiver personal life	Personal activities renouncement
		Social isolation
		Life <i>in pause</i>
	Physical health	Tiredness
		Physical effort
		Sleep problems
		Postpone of own's health care
	Psychological health	Emotional stress
		Dealing with diagnosis
		Felling alone
		Decision making process
<i>Dementia related costs</i> Costs introduced by the disease that affect family overall financial budget – all the economic expenses that are related of the condition of dementia	Food issues	
	Hygiene issues	
	Electricity	
	Medication/medical exams	
	Formal care	Day center
		Nursing home
		Formal caregiver
	Transport	
<i>Formal care services</i>	To cheat person with dementia	
	Lack of financial support	
	Home support services	Support in personal hygiene

Changes daily routine related to formal care services (home care support, formal caregivers, day center, nursing home)	Day center	Positive /negative aspects
	Nursing home	Positive /negative aspects
	Barriers to access formal care	Costs
		Limited spaces
		Long process
		Person with dementia will/preferences
		Transport/road accesses
	Lack of formal support	Targeted care for person with dementia

Quality of life

Across all focus groups, caregivers' perceptions focused aspects related to their quality of life (*Table 1 of Additional file 3 of Supplementary material* for more examples):

- *"There is no quality of life at all ..."*, Caregiver, female (daughter), Focus group A, line 1374.

In fact, the changes that taking care of a person with dementia brought to the personal life of caregivers were thought of as highly relevant, leading to complex adjustments at several levels: i) professional changes:

- *"So in the beginning, let's say it was a bit difficult, because I was working, I worked at night, [...], so now I work in the morning so that I can be with her [the mother] at night ..."*, Caregiver, female (daughter), Focus group D, lines 5460-5462;

- *"Yes, I suspended my activity, yes..."*, Caregiver, female (daughter), Focus group C, line 4201.

1. ii) couple's life commitment and household changes:

- *"[Problems with...] my husband, yes... In fact, great contradictions in terms of managing the [caring] situations, and today I would say no, that I would not accept... [receiving the in-laws in her house]."*, Caregiver, female (daughter-in-law), Focus group C, lines 5155-5156.

iii) social isolation:

- *"(...) our social life disappeared completely, because our friends do not go to my house anymore, I stopped inviting people to go there..."*, Caregiver, female (daughter-in-law), Focus group C, lines 4697-4699;

- *"My friends don't want to know..."*, Caregiver, female (daughter), Focus group C, line 4701;

To avoid loneliness, some caregivers tried to include the patient in their social activities (which could be beneficial for both). However, the patient's behaviour can bring difficulties:

- *"(...) we went out for dinner, twice, and then he panics, he panics, I had to leave and my daughters stayed at the restaurant... Now, I never go out to have dinner with my daughters ..."*, Caregiver, female (wife), Focus group C, lines 5265-5267.

Over time, caregivers are entirely moved away from their personal life and, in most of the cases, the social isolation and feeling of abandonment due to the loss of old friendships can be meaningful.

The routine of caregivers can drastically change when the caregiver has to leave their house to stay in their relative's house (the most common situation, Table 1). Most of the participants admitted being single caregivers, which resulted in having no spare time for themselves, for having activities besides caring. Some caregivers even expressed their sadness for having stopped doing their usual activities, putting their life in "standby":

- *"(...) I will never have a life of my own again..."*, Caregiver, female (wife), Focus group C, lines 4645-4646;

- *"(...) I travelled almost every year, [...] we had a group of friends and we travelled, now I don't do that anymore..."* Caregiver, female (daughter), Focus group D, lines 6646-6647.

Caregiving tasks and routines had also major impact in both the physical and the psychological health of participants who affirm to be very tired:

- *"Exhausted! Completely exhausted! [...] I have health problems too (...)"*, Caregiver, female (daughter), Focus group B, lines 3574-3575.

Being the only caregiver also led them to postpone their health care. They are continuously worried about their relative's well-being and their own health come second and most of the participants admitted having faced health problems:

- *"A person does not have time for anything, anymore. I need to go to the doctor and I won't (...)"*, Caregiver, female (daughter), Focus group A, lines 1905-1906.

Some participants referred that the moment of diagnosis brought high emotional stress with some of them expressing the necessity to receive more information and guidance. Learning more about the

disease evolution was reported to could be felt as useful so they can be prepared to better deal with specific situations, while reducing the related burden. Not being recognized by the relative with dementia is something that scares and saddens the caregiver.

- *"(...) At that time, it was a shock for me..."*, Caregiver, female (daughter), Focus group D, line 5428;

- *"(...) in the beginning, it was not explained to me what Alzheimer's was..."*, Caregiver, female (daughter), Focus group D, line 5431;

- *"I would like to learn more about everything because a person starts from scratch!"*, Caregiver, male (husband), Focus group C, line 4847.

- *"(...) I thought, 'Okay, will my mom forget me?' ... It was one of the things that I was afraid of (...)"*, Caregiver, female (daughter), Focus group D, line 5433-5435.

Keeping up the daily routine was a widely discussed topic as something that the person with dementia needed to be involved in, on their daily lives, so s/he may feel well:

- *"They need routines, that's what I notice, anything ..."*, Caregiver, female (daughter), Focus group C, line 4548.

The night period is the moment of the day that demands more from participants. Some person with dementia can become very agitated, walking around the house and turning the lights on, which was referred to as having negative implications for the caregiver's sleep and rest:

- *"(...) I can rest a little during the day, I don't get enough sleep at night, I don't sleep more than four hours straight (...)"*, Caregiver, male (husband), Focus group A, lines 853-854.

Altogether, the insufficient rest, the large amount of duties, the delay of self-health vigilance and the absence of personal/social life, were referred to highly contributed to a negative impact in caregivers' quality of life.

Dementia care-related costs

The topic of dementia care-related costs was raised altogether with daily challenges and experiences (*Table 2 of Additional file 3 of Supplementary material*). All participants expressed their general disappointment for the excessive lack of financial and social support, both for the person with dementia and the caregivers. However, there are significant financial costs, as participants admitted to spend their life savings month by month, due to their caregiver function, which is seen as a potential difficulty for the future:

- *"I am putting my money, at the moment, [...] it is money that I may need someday, right?... I'm putting around €400..."*, Caregiver, female (daughter), Focus group D, lines 6598-6599.

Having an economic support was, therefore, highlighted as an important aid for participants. This is especially relevant because most of the participants were retired or not working (also due to their caregiver activity, incompatible with a paid professional activity), which significantly reduced their monthly income. The economic assistance available from the Portuguese State from which they can benefit is referred to be very bureaucratic, hard to obtain and not covering all the expenses. Overall, participants have to pay the daily expenses such as food, hygiene products, house bills and medicines and, only in some situations receive some family support:

- *"The worst are the costs! That's right! For the costs [formal care services], they ask us between €900-€1000/month... where do I get it from? I have things to pay, I have water, electricity, telephone, gas bills... Not to mention food, shoes, clothes and medicines... If I take these €900 or €1000/month, I get...nothing! And what do I do with the rest of the other things?"*, Caregiver, female (daughter), Focus group D, lines 6613-6616;

- *"(...) I can't take €1000/month to pay a woman [formal caregiver] ..."*, Caregiver, male (husband), Focus group A, lines 1898-1899;

Also, hygiene products (e.g., the need for diapers and wet cleaning wipes) and medicines is described as a high burden:

- *"(...) Just for medicines, just for my husband, I spend €150 a month... apart from my own medication, which I am no longer count!"*, Caregiver, female (wife), Focus group C, lines 4313-4315;

- *"Much [money]! And then more wet cleaning wipes [...], her hygiene must be more, more than just diapers!"*, Caregiver, male (husband), Focus group A, line 1510.

To reduce the monthly financial burden, some caregivers resort to generic medication, which is negatively perceived by caregivers:

- *"(...) It is like this...it is generic medication, if it is not generic, it is a lot of money! I had to go to a generic brand! ...Unfortunately!"*, Caregiver, female (daughter), Focus group A, lines 1538-1539.

Another problem relates to the difference between the total amount of the monthly income from person with dementia retirement pensions and the costs of needed formal care services, which is considered, by participants, as unaffordable:

- *"(...) My mom has a €400 pension, [...] If you are going to pay €1000/month by the nursing home it is a shame! It is a shame!"*, Caregiver, female (daughter), Focus group C, lines 5083-5084;

- *"There is a big problem here, I think, of pensions, for the majority of the Portuguese, who are poor, and €500 [of pension] is already a lot of money,(...)"*, Caregiver, female (daughter), Focus group C, lines 4322-4323.

The lack of financial support for these patients and their caregivers was extremely evident and discussed, with caregivers sharing their multiple attempts to request financial help. The caregiver finds him/herself alone, without psychological and financial support and without adequate formal answers for their daily problems:

- *"I did not have any help, I have not received it, that's what I think I should claim that there should be. I learned that there is not, and even if the person searches and searches... There is not. I felt completely naked, in the sense of, the person looks for something and there is not!"*, Caregiver, female (daughter), Focus group B, lines 3512-3514;

- *"(...), my brother [person with dementia] does not have any financial support...I think that he really needed..."*, Caregiver, female (sister), Focus group A, lines 1970-1971.

Some caregivers admitted careful management their mensal budget, avoiding some expenses (e.g. social and leisure moments, medical appointments). Other costs were reported by caregivers (*Table 2 of Additional file 3 of Supplementary material*), such as high electricity bills related to the daily need of laundry all the linen and the patient's clothes. Earlier stages of illness revealed an extra and unexpected expenses, such as frauds or thefts, more easy to happen due to patient's state of confusion. Indeed, different events were provided as examples of how easy it is by strangers to take advantage of person with dementia conditions. Another example of loss of money are the situations where the person with dementia is deceived and encouraged to sign service loyalties (for instance mobile and internet plans) which they could not use and that resulted in large losses of money.

Overall, considering the weak economic environment of caregivers due to a lack of adequate financial support, high costs related to dementia care and the difficulty to be employed or having a part-time job, the financial burden is an important issue that caregivers face, besides the caregiving tasks.

Formal care services

Many caregivers expressed their opinions regarding the problems in having access to formal care services (*Table 3 of Additional file 3 of Supplementary material*). One of the first barrier was participants previous bad experiences and stigma involving nursing homes, that were often not considered as a good option in what concerns to long-term care for their relatives:

- *"They [the person with dementia] did not even come outside [into the gardens]... that was a deposit [of people]... [...] That shocked me and I took her [out of there]..."*, Caregiver, female (daughter), Focus group C, lines 4139-4140.

Some caregivers admitted the possibility to rely on a nursing home only when they consider that the nursing home has the adequate conditions. However, in their opinion, good services at a reasonable cost do not exist, which is seen as a main barrier for leaving their relatives there:

- *"It depends on the nursing home, if I find a good home by a reasonable cost within the budget that my mother can afford to pay [...], but the problem is that there is nothing like that..."*, Caregiver, female (daughter), Focus group C, lines 5114-5115;

- *"It is also out of question, monetarily, you see... [reason to not consider the nursing home]"*, Caregiver, female (daughter), Focus group C, line 5100.

Even when a nursing home is the most adequate solution, the fear and mistrust regarding this type of institution can hinder the decision towards institutionalization:

- *"(...) mine [her mother] will not go to a nursing home, [...] She is afraid!"*, Caregiver, female (daughter), Focus group A, line 2949.

So, institutionalization is considered a resource for person with dementia only in advanced stages of the disease (when not having other alternative). This solution is seen as a failure of caregivers' responsibilities (since, culturally, to care for family members is considered by participants as a family duty), with the decision-making process of opting by institutionalization described as very hard:

- *"(...) I was tired of crying because it was going to be hard for me [the moment of her mother's institutionalization] ...It was too far from my house (...), you know?, Caregiver, female (daughter), Focus group B, lines 2627-2630.*

The long bureaucratic process, the limited number of available places (in nursing homes), the distance from home and long waiting times to be accepted by nursing homes, all these were also seen as strong reasons to not preferring to put their loved ones in a nursing home:

- *"(...) today I don't have this document, tomorrow I don't have another one, then another one is missing, it's just bureaucracy!..."*, Caregiver, female (wife), Focus group C, lines 5103-5104;

Summing up, the patient admission to nursing homes is seen as a difficult, time-consuming, and a painful process. Therefore, most participants tend not to consider this as an option. However, despite of the mentioned obstacles, when considered, the institutionalization brings a new opportunity for the caregiver to regain their live:

- *"I now feel calmer, because I was always nervous and anxious [...] and I feel that I have more time to do things that I did not have before..."*, Caregiver, female (daughter), Focus Group B, lines 3527-3529.

Formal care services, such as home-based support care was welcomed by participants, that found in these a good solution for taking care of the personal hygiene of their relatives, especially when they had physical limitations. Additionally, having their relatives in a day center (5-6hours/per day), allow then to have some spare time for shopping, going to medical appointments, do physical activity, or rest:

- *"Yes, as they entered the day center that brought me back time for my yoga, for going to the gym and got my [head] back to work, I think, normally..."*, Caregiver, female (daughter-in-law), Focus group C, lines

At the same time, attending the day center was positive also for the persons with dementia, since they get to be engaged social activities, create a routine and are in a safe environment, which is a relief for caregivers:

- “[...] *they have activities, they have gymnastics, they can cook, [...] they go for walk, they attend to theatre shows [...]*! So, my mom has now a more busy social life than I do! (laughs)”, Caregiver, female (daughter), Focus group C, lines 4974-4977.

Another emphasized characteristic of day centers (although this happens only in a minority of them) is to have specific locations dedicated to person with dementia, with closed doors. This was very emphasized by the participants as an aspect of major importance for their relief and their relative’s well-being:

- “*As in my case, my sister left one day [run away from the day center] ... So, she is now here [closed door floor, in the day center where the focus group was running], precisely because there is absolutely no danger...*”, Caregiver, female (sister), Focus group C, line 4150 and 4154.

Overall, day care centers were mostly referred as very positive for the daily lives of both patients and caregivers, and it was only regrettable, by participants, that only a minority of facilities is truly adapted and directed towards people with dementia needs.

Map of factor affecting caregivers’ daily life experiences and quality of life

Based on the coding system, frequency of codes and a review of the quotes sorted by category, a model was developed to better describe the burden of dementia in caregiver's daily experiences quality of life (Figure 1). Caregiving experiences shared by participants revealed that the process of caring of a person with dementia has an enormous impact at several levels: individual, familiar, social and professional.

The psychosocial characteristics and interpersonal skills of the person with dementia, as well as the general health and the progression of the disease define an important part of informal caring since it can mean more or less burden to the caregiver. During the process of care, the related costs of dementia and the high number of barriers accessing formal care services can significantly modulate the impact of caregiving in caregiver’s quality of life.

Discussion

This study aimed to explore the perceptions of informal caregivers about the experience of taking care of a person with dementia, to better understand its costs on different dimensions. Overall, the financial costs, the lack of adequate support from formal care services and each family’s functioning idiosyncrasies, profoundly disrupted by the emergence and aggravation of dementia-related conditions have a tremendous impact on caregiver’s quality of life.

Being a full-time caregiver for a person with dementia significantly change the caregiver's life. The moment of diagnosis comes unexpectedly, despite the slow onset of symptoms. After the diagnosis, the need of vigilance and help to perform everyday tasks require the presence of the closest family member. As described in other studies, we also found that the daily difficulties tend to worsen as the disease progresses to its latter stages [35]. The duration of care in our study ranged from 2 to 15 years, with different difficulties related to the stages of the disease. The physical burden was present as early as the caregiver assumed his/her role, showing that caregivers physical well-being is widely affected from the beginning of care and worsen with time. The postpone of their health care monitoring due to the excessive time dedicated to taking care of the person with dementia increases the probability of caregiver's health complications, that latter result results in serious health problems. Physical tiredness can be explained with the effort required to perform strenuous tasks such as personal hygiene, helping to get up/out of bed and dressing/undressing the patient. Also, most of the participants had health problems, and several referred that the resulting sleep deprivation tends to affect caregivers' well-being. Indeed, sleep disturbances in caregivers of person with dementia has been a well-studied issue and findings from Peng *et al.*, indicated that more that 90% of the caregivers had poor sleep quality [36]. This is in accordance with our study that show that, even when the caregivers were younger, the severity of health conditions did not decrease when compared to the rest of the participants and sleep deprivation was always present. So, more years of care revealed a more tired and lonely caregiver, with less physical and psychological capacity to continue the role. A relevant study of Greenwood *et al.*, discusses some of the topics related to the main worries expressed by caregivers participating in our focus groups, highlighting a concern about what happens to person with dementia when caregivers can no longer care, due to age or health complications [37]. That concern was verbalized by the participants in our study, mainly when caregivers were the only family members available to care for the relatives.

According to the narratives collected in our study, not only physical health, but also the psychological well-being of caregivers was compromised throughout the caregivers' career. This has been documented in several other studies: dementia seems to modify the quality of life of caregivers, with serious impair on psychological health due to the daily emotional stress and burden experienced during care [38–41]. In the process of care, most of the day of caregivers is dedicated to the person with dementia; the caregivers' personal and social life is put off, leading to social isolation, and feeling of loneliness are typically reported [41, 42]. In our study, most of the caregivers were the only caregiver and receive few help from family members, restricting their time to caregiving tasks only. However, when other family members are present, caregivers can use some time to do their own activities, like going for a walk, shopping or being with friends. Supporting the caregiver on its role is crucial, since there is evidence suggesting that caregivers of persons with dementia are more exposed to suffer significantly higher levels of psychological morbidity and stress [11–13]. This fact might be related to the emotional impact of dementia in caregivers that are aware of the physical and mental decline of the patient, more than being aware of the physical and psychological deterioration of the patient herself. Moreover, due to the familiar bounds, witnessing disease progression and not being recognised by the relative with dementia seems to be one of the hardest things to manage for the caregivers included in our study.

The person with dementia is widely compared to a child, given the need to be continuously cared [35, 43]. This phenomenon of reversing or modifying roles (the daughter/son caregiver becomes the mother/father of the person with dementia; the wife/husband that becomes mother/father) was something considered as tough to deal with, especially when the caregivers had their own daughters or sons, due to the great effort required to this multitudinousness of care. Additionally, since caregivers are frequently women, there is the responsibility to take care not only of the family, but also of the home-related issues like cooking, cleaning, and so on. So, due to all chronic and emotional strains, caregivers may undergo to emotional exhaustion and burnout, as previous reported in other studies [44, 45].

Despite the initial struggle, in our study, caregivers start to learn, with time, how to handle the daily struggles, while adapting his/her own personal and professional life. However, this adaptation requires that caregivers become fully dedicated to the care of the person with dementia. The fact that caregivers are unaware of the behavioural changes that the person with dementia might develop with the disease progression, seems to make it harder to handle with the aggressivity, hallucinations and constant humour change. Evidence suggests that there is a strong impact on the quality of life of caregivers with the increasing of behavioural symptoms [46]. Besides, the constant mood fluctuations of patients can thoroughly change the daily routine, since the patient can be more receptive to contribute or not with eating, bathing, walking, and so on. This daily instability also contributes to the caregiver's physical and emotional stress.

An interesting study showed that the caregivers consider that: ensuring the safety of the person with dementia and managing their own stress are goals that can transform their task into a more positive and less impacting task [47]. This is in accordance with our results since relative's safety was of high importance for the caregivers, as well as, learning to deal with their own stress and emotions.

Another widely explored and consensual theme in the literature was the financial burden that dementia brought to the family and caregivers [48–50]. The high costs of dementia makes this one of the most expensive diseases for families, due to the need of a full-time caregiver. When the caregiver is the closest family member, it might involve professional changes (reduction of working hours /quit jobs), and consequently, lower financial income. Despite that, it is culturally accepted, in Portugal, that caring for the loved ones is a duty of the family, and besides the negative aspects that it brings, the caregivers of our study tend to choose caring for the person with dementia over institutionalization. There is a long-standing idea that informal caregiving has less costs than formal care, however, the dementia-related costs are hard to cover without a job, in some cases, with huge negative impact on caregivers' daily living. So, caregivers need not only to care for their relatives but also to ensure the economic income to cover all the related costs. Caregivers participating in our study shared the fact that they need to use their life savings to cover for the expenses related to dementia, with an obvious impact on families sustainability for the future.

Interestingly, caregivers who participated in our study were practically unaware of how to obtain support from the national health and welfare system. Even when they knew how to and attempted to do it, they

faced a long and bureaucratic course to unfinished paperwork and no support, being referred to be a demotivating process. The expressed misinformation on financial support is in line with the results from previous studies which show the lack of professional support and guidance in this particular area [22, 51]. Additionally, this lack of support and information occurs from the moment of diagnosis and initial stages of disease. After the diagnosis, caregivers expected more help from health professionals, in terms of description of the disease progression, what to expect and how to deal with the disease. Instead, caregivers reported they had to learn all about dealing with dementia by themselves, making the task harder.

The most difficult financial cost for all caregivers to bear was related with formal care services and, particularly, the cost with nursing homes, as described in other studies [52–54]. This obstacle, together with the common negative opinion about nursing home services, resulted in a huge barrier that pushes nursing homes to the last resort for caregivers [22]. Some caregivers expressed their surprise when the topic about the possibility to apply to formal care assistance, because they were already in financial struggle and cannot cover the costs of these services. Interestingly, one of the cheaper formal care services available (day centers), were the best suited solution for the included caregivers, due to their better adaptations to cover dementia patient specific needs ensuring their safety.

A study from Tretteteig *et al.*, highlighted the importance of day centers in meeting the person with dementia' needs, namely when allowing social integration, nutritional balance, physical activity and daily regular routines [55]. The fact that day centers helped to reduce the patient aggressiveness episodes and, indirectly, helped caregivers by reducing the associated burden was previously documented and also present our study [55]. The positive appraisal by caregivers and great impact on patient's well-being, should prompt studies that explore the relevance of day centers adapted for person with dementia in society. The relevance of nursing homes and formal caregivers was seen, by some of the participants of our study, with disappointment and distrust due to the inadequate adaptation to patient needs and caregivers' financial budget. The opinion that nursing homes are not prepared for person with dementia and the need of some adaptation to support the course of dementia is shared in other studies [22, 51, 56].

Costs of medications and medical exams were referred as a relevant source of expense in our study and widely published in literature [57]. To overcome that, the caregivers resorted to the cheapest drugs on the market: generic medicines. However, there is a underuse of this medication in Portugal that might be related to: the level of education, low health literacy and lack of information by clinicians [58]. To decrease the negative appraisal on this topic, more information and prescription should be encouraged, particularly when the caregiver itself also has health problems, resulting in a large monthly expense.

According to the present study, the task of caring for a person with dementia requires a comprehensive plan that might gather and articulate support at different levels (including social, financial, juridic and psychological), for both the caregiver and the person with dementia. So, a partnership among clinicians, healthcare workers, social workers and family members is required, endorsing a systematic and integrated experience of caring for person with dementia. Caregivers' perceptions about the related costs

of dementia caregiving are crucial to develop target interventions for this community and to reduce the negative effects on caregiver's quality of life, while maintaining a good care and promoting patient's quality of life as well.

An effective and sustainable informal healthcare approach, focused on the early promotion of caregivers' skills (i.e., with training and dementia care related literacy promotion, starting as soon as the possible when the patient is diagnosed), closer medical monitoring and optimised financial support is needed to contribute to caregiver's well-being, improve formal care response and minimize the familiar financial burden caused by dementia. A home programme such as the "Going to Stay at Home" is the perfect example of a feasible and practicable model that helped both caregivers and persons with dementia, delaying the institutionalization over 12 months, while decreasing the unmet needs and behavioural symptoms in persons with dementia [59]. Additionally, also the caregiver's and patients' unique clinical and personal aspects are important, showing the need of custom interventions to meet the specific needs of each family [60]. So, knowing that the number of people suffering from dementia is expected to increase in the coming decades, multidirectional interventions and programmes are needed to prevent a future burden and impact in informal caregivers of people with dementia.

Conclusion

Dementia informal care included a wide range of experiences referred by the caregivers about the disease and about the proper way of caring, as well as the drastic changes introduced in their personal lives, and all this seems to represent important difficulties that may hinder a proper care for the person with dementia. Caregivers' perceptions about the related costs of dementia caregiving are crucial to develop target interventions for this community and to reduce the negative effects on caregiver's quality of life, while maintaining a good care and promoting patient's quality of life as well.

Strengths And Limitations

The strength of this study is the description of the phenomenon of caregiving of a person with dementia through informal caregivers' views, focusing their daily life experiences.

The main limitations of this study were: a) the scarce time of caregivers conditioned by the severity of their relatives disease , leading to the inevitable exclusion of the most severe cases (caregivers of persons with dementia in advanced stages); however, caregivers of different stages of disease were included in this study; and b) the focus on a single urban area of the territory can be seen as a limitation; however, the sample included different living situations, familiar relationships, ages, professional status of the caregiver, different times of diagnosis and stages of severity to be as much representative of the phenomenon as possible.

Declarations

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Availability of data and materials

The dataset supporting the conclusions of this article is included within the article (and its additional files 1 and 2 of Supplementary material."

Ethics approval and consent to participate

All procedures performed in the study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Participants voluntarily enrolled in the study. Written consent forms were available and each participant provided informed consent. This study was approved by the competent Ethics Committee (Centro Académico de Medicina de Lisboa - CAML) in October 2018.

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Author contributions

PL recruited and invited the participants. OS and PL moderated the focus groups. AV took written annotations in the field. PL, AV and OS transcribed and analysed the data. All authors were responsible for the study conception, design, drafting and reviews the manuscript. MMR and MG supervised the study.

Conflict of interest

The authors have no conflict of interest to report.

Consent for publication

Not applicable.

Competing interest

None declared.

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Figures

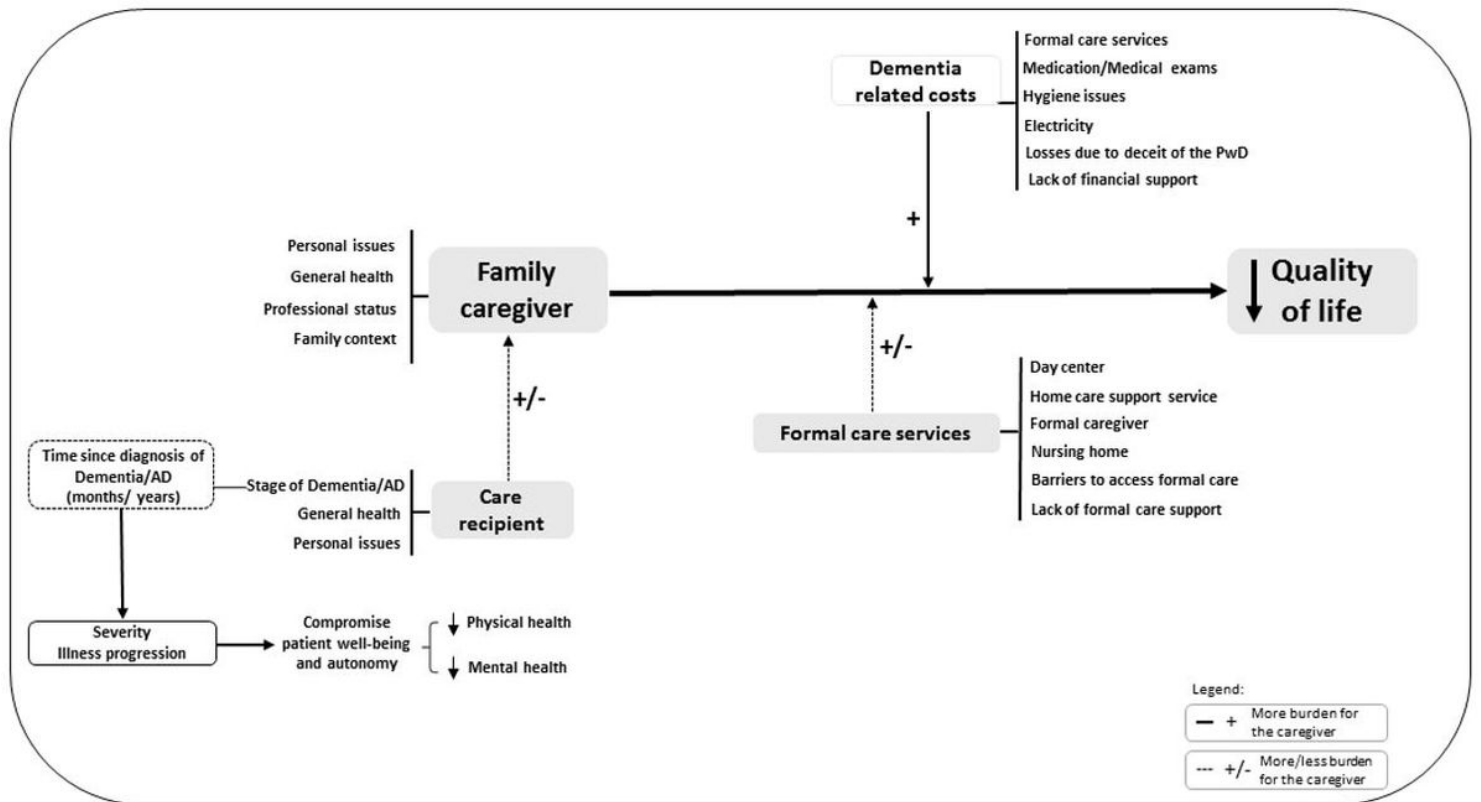


Figure 1

Informal care impact to caregiver's quality of life

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