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REVISTA IBERO-AMERICANA DE SAÚDE E ENVELHECIMENTO
REVISTA IBERO-AMERICANA DE SALUD Y ENVEJECIMIENTO

THE DAILY LIFE OF INFORMAL CAREGIVERS OF ELDERLY

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VOL. 1 N.º 2 AUGUST 2015

ABSTRACT

Objectives: To identify the reasons why the informal caregivers to take care of the elderly; to identify enjoyed support and the problems/needs senses. **Methods:** A descriptive, exploratory and cross study. The sample was 366 informal caregivers of the elderly residents in the District of Évora (Alentejo). Applied a questionnaire, which identified the reasons that led to cohabitation, the difficulties experienced by caregivers, experienced changes in their health and support they receive. **Results:** Most caregivers are women, with a mean age of 54 years. The main reason of care was elderly disease. These caregivers have changed in relaxation and leisure activities, on the organization of day-to-day and on economic aspects. They receive support from health institutions, social security and firemen's. **Conclusions:** Family is the support in the disease, despite the difficulties, particularly in relaxation and leisure activities, organization of day-to-day and economic matters. They requested support in healthcare, transportation and economic aid.

Descriptors: Home nursing; family; elderly

INTRODUCTION

Despite it is started in the last century, in recent years that has become more visible the progressive aging of the population. The world's population will keep the aging process, so it is expected that it exceed 9 billion by 2050 (United Nations, 2007).

Portugal is also not out of the phenomenon of aging. Between 2001-2003 and 2011-2013, the life expectancy at birth has increased, reaching women 82.9 years-old and men 76.9 years-old. In the period 2011-2013, life expectancy at age 65 was estimated at 18.97 years-old for both sexes, namely 17.07 years for men and 20.40 years for women (Carrilho & Craveiro, 2015). Recent data show us that the Portuguese population with 75 or more years old in the total population rose 7.0% in 2001 to 9.7% in 2013 and the proportion of the elderly (80 or over) in the elderly population in 2013, amounts to 27.9% (Instituto Nacional de Estatística [INE], 2015b). In Portugal, from all regions, the Alentejo is the one that has the highest aging index (180.7) as well as the elderly dependency ratio (38.6) (INE, 2015a).

Technological developments, the advancement of science, improvement of living conditions and socioeconomic have contributed unequivocally to increasing population longevity, which sometimes is associated, at an older age, a higher prevalence of chronic diseases and disabling that create some level of dependency in carrying out daily activities.

Regardless of whether they can reach old age without disease, over the years it is likely that health will deteriorate, or be weaken, because of normal distress, caused by the passage of time, conditioned by the individual characteristics and surroundings, demonstrating some need help.

Many families remain a firm commitment to provide care and support to their elderly relatives. Eventually this could lead to an adjustment to current family structures, more fluid and a further strengthening of family ties, calling into question the public apprehension that the families are unavailable to care for the older (Harper, 2009).

Despite the family caregivers be a resource, they have needs and problems inherent in the care of an elderly relative, then they are known as hidden patients. They too need help to promote their quality of life, health and well-being, for providing care for a long period of time, especially the dependent elderly, can be physically strenuous and psychologically (Figueiredo, Lima & Sousa, 2009).

Informal caregivers are considered "family members, friends, neighbors or volunteers who provide unpaid care shape" (Figueiredo, 2007, p 103). Such care is "carried out preferably at home and usually are under the responsibility of family members, friends, neighbors or others, being called informal caregivers" (Sequeira, 2007, p 97).

Among informal primary caregiver, it is considered the one who bears absolute responsibility of supervision, guidance or care directly from the person who needs care, that is, one who performs and is responsible for most of the care (Sequeira, 2007).

Kalache (2009) refers that is not worth using euphemisms, women, especially older women, sometimes sick, cares their home, continuing to support the community's main task in any country.

Sequeira (2007) mentions that the literature suggests that as a result of an aging population plus the number of elderly caregivers, which sometimes leads to physical limitations inherent in the aging process so the activity of taking care is a factor with physical and mental morbidity. Informal caregivers are characterized by an advanced age, i.e., they are elderly, married, female, spouses or daughters, with low education, without occupation, low-income and usually coexist.

The negative consequences attributed to the fact that caregivers also have an advanced age and not developing an occupation is a controversial issue because, according Sequeira (2007), the authors did not have a unanimous opinion; some consider that the young are most vulnerable to the difficulties inherent in providing care. Also in relation to

employment status, for those who have no occupation that caring can be an opportunity for personal fulfillment and those who have it can serve as an outlet for the release of the stress inherent in providing care.

According to Figueiredo and Sousa (2008) and Figueiredo et al. (2009) family caregivers of dependent elderly people are less satisfied with life and perceive their health as being worse. The overhead is high for the caregivers who consider their health status as poor (more nervous, more depressed, sadder, less calm, less happy), especially when the elderly have dementia. Family caregivers of elderly without dementia described their mental health as significantly better. Caregivers who have a less favorable perception of their health status are those who feel overburdened in their role. Therefore, the overload resulting from the context of providing family care to the dependent elderly seems to have a negative effect on their health. The success or failure of care provided by informal caregivers relies extensively on the formal support available to them, thus allowing the maintenance of the elderly at home and in the family does not enshrine a hard task, and may constitute a source of satisfaction.

Lopes (2007) brings together the difficulties as follows: those that arise from ignorance of existing services that respond to the different needs and problems presented by the elderly in situations of dependency, and difficulties in accessibility to existing services, hospital discharges without support to enable continuity of care and home support not tailored to the dependent person's needs. Thus, it is clear the importance attached to information about the formal resources that exist in the community to support informal caregivers. Investment in programs for informal caregivers should be a priority, as the awareness of health professionals and social support for a network intervention (Alves et al., 2015). Martins, Corte and Marques (2014) reinforces the need for health professionals to invest in promoting the abilities and skills of informal caregivers in order to minimize the negative impact, sometimes associated with the caregiving.

METHODOLOGY

It is a descriptive, exploratory and cross-sectional study with a quantitative approach. The target group are 366 informal caregivers of seniors who cohabit with them, over 18 years-old and who lives in the District of Évora (Alentejo). We intended to know the reason why care of the elderly, whom they cohabit with, what support they enjoy and the problems and felt needs.

A criterion for inclusion is the primary caregiver not be the spouse of the elderly, considering elderly any individual who is 65 years old or older, regardless of health status or level of dependency.

For data collection, we selected questionnaire survey. In the first part, the questions allow you to make brief sociodemographic characteristics of caregivers and even the elderly that is taken care of. The second part brings together a set of questions through which we intend to know what the experience of these families and the third part is intended to understand which helps the formal network available to them.

We proceeded to descriptive statistical treatment of the data by using the Statistical Package for Social Sciences (SPSS®) 18.0.

Descriptive statistics were used and resorted to statistical tests, in particular Spearman correlation coefficient test, and in concordance with the coefficient of Kendall's W test and Friedman test, whose algorithms allow sort the answers and see if this order is significant.

All ethical procedures were met (informed consent, confidentiality and anonymity) as the Helsinki Declaration on Ethics in Research Involving Human Subjects. Permission was obtained from the Alentejo Regional Health Authority.

RESULTS

Informal caregivers of seniors who agreed to participate in the study (366) characterized by being mostly female (88%), daughters, with an average age of 54 years old, most women are married or living in union (73.5%), the majority of aggregates is composed of three elements (41.3%). These are people who have essentially the first cycle as educational qualifications (40.7%) and work for others (33.6%), although, if we join the unemployed, pensioners and housewives, i.e., those who do not develop any professional activity, this number corresponds to more than half of respondents (54.9%).

Mostly these families care for their parents (79.5%), mainly women with an average age of 83, where a quarter of seniors has more than 87 years old.

The results show that it is mainly a long-term cohabitation on average about 19 years. Most of the time, these seniors do not circulate in the home of other family members (80.3%), when they do it is in the house of other children, most of the time, every month.

To assess the relative importance of the reasons why these people have decided to care for their elderly relatives and they live with them, the data to Kendall's test W. were submitted according to the results. It can be concluded that this ranking is significant ($p= 0.000$) and that for these caregivers, the main reason that prompted them to take care of elderly family member is their disease (4.74). Following this hierarchy the previous cohabitation (4.30) and isolation or loneliness (3.99) were arisen. Moreover, it appears that the need of family (3.63) was the reason given with lower relative importance, as can be seen in Table 1.

Ranks		Test Statistics	
Main reason	Mean Rank		
Elderly disease	4,74	N	366
Previous cohabitation	4,30	Kendall's W ^a	,090
Isolation / loneliness	3,99	Chi-Square	197,482
Family convenience	3,89	df	6
Duty/ obligation	3,78	Asymp. Sig.	,000
Love/ Affection	3,68		
Family need	3,63		

Table 1. Main reason why the elderly live with family

Source: SPSS

The constraints inherent in providing care and the difficulties and obstacles they face in everyday life are pragmatic issues that arise for informal caregivers of seniors. It was interesting to note, in the opinion of these caregivers, what are the main changes or difficulties they faced in day-to-day because they take care of the elderly and understand the relative importance of the same, so the data were submitted to the Friedman test. Given the results shown in Table 2, it can be concluded that for these caregivers major changes or difficulties relate to the rest and leisure activities (8.28), difficulties in organizing the day-to-day family (7 , 82) and economic hardship (7.43). Difficulties due to lack of time to pay attention to the elderly (3.83) in the opinion of these families are the ones with lower relative importance.

Ranks		Test Statistics ^a	
Daily changes/ difficulties	Mean Rank	N	366
Rest and leisure activities	8,28	Chi-Square	927,809
Difficulty in organizing daily	7,82	df	10
Economic difficulties	7,43	Asymp. Sig.	,000
Conciliation family/professional life	6,73		
Lack of information	6,06		
Lack of support and help	5,79		
Property conditions	5,39		
Relationship with elderly	5,08		
Conflicts	4,80		
Lack of Technical Aids	4,80		
Lack of time to pay attention to the elderly	3,83		

Table 2. Main daily changes/difficulties

Source: SPSS

We can also conclude that more than half of caregivers did not divide the responsibility of caregiving with other elements (57.9%), mainly for not feel need for it and when they do it is mostly with their spouse.

The fact that care for the elderly, in the perception of these caregivers, has aggravated little or never his state of physical or mental health. Most caregivers felt that their physical health was affected in "nothing" (37.7%), as seen in relation to their mental health (42.3%). It can also be seen that more than half of caregivers (67.2%) report having been "little" or "never" physically affected by the fact that caring for the elderly. The same applies to their mental health status therefore more than half of the families (68.3%) think they suffered "little" or "no" changes. We must not neglect those who had the perception that their physical and mental health have worse "much" or "very much", respectively 22.7% and 22.4%, very similar values. For them, the tiredness and exhaustion may be eminent.

It was found that there is an association between the age of the caregiver and the deterioration of physical health status (Spearman's rho 0.281 **; p = 0.000) and mental health status (Spearman's rho 0.147 **; p = 0.005). On the other hand, there is a negative association between the worsening state of physical and literary caregiver qualifications (Spearman's rho -0.213 **; p = 0.000) and the number of household members (Spearman's rho -0.105 **; p = 0.045). The deterioration of physical health is also associated with age of the elderly (Spearman's rho 0.221 **; p = 0.000). It should be noted, however, that these associations are very weak.

More than half of family caregivers (65.8%) receive support from the formal community institutions. From these ones, the Health Centre, Social Security and the Fire are so much

important. Family members who refer they do not receive any support from institutions have mentioned they do not need it.

For aid or care provided by these institutions, they point out health care (nurses and doctors), highlighting the nursing care as well as economic aid.

Most caregivers were attended when requested institutional support (65.3%), where this did not occur the main reason was the lack of space. For the adequacy or appropriateness of the support, the majority considered sufficient or appropriate (54.6%). Those who expressed different opinion related essentially the lack of economic resources and inadequacy of times.

DISCUSSION

The profile of caregivers who participated in the study is commonly found, both nationally and internationally for decades. Informal caregivers are mostly women, who in the near future will be older, married and with a low educational level. A recent study confirms the predominance of women, married or in union, with low education, mostly living in the same room with the receiver of care (Alves et al., 2015).

The fact that they already are in an old age may hinder the provision of care, especially if the elderly are dependent, because their own caregivers may also experience changes in terms of their health. On the other hand, education can also be a constraint because, as mentioned Brito (2002), caregivers with higher education showed fewer difficulties in care.

Although the majority of caregivers work for others, those who do not develop any professional activity account for more than half. The accumulation of paid work with caring role does not constitute the predominant model, as happened in other studies (Brito, 2002; Lage, 2005; Sequeira, 2007; Veríssimo, 2004).

The average age of these seniors is 83, mainly women. The greater longevity of women and the aging of the elderly population contribute to this situation. It is most notorious female predominance both in caregivers, as those who are cared. Studies confirm it (Brito, Grácio, Calvário & Brito, 1999; Figueiredo, 2007; Paúl, Fonseca, Martín & Amado 2005; Salgueiro, 2008). As in the study by Alves et al. (2015) on the relationship between those who care and those who are cared, it appears that a majority are children.

The study results show that this care tends to be a long-term undertaking, such as in the study of Lage (2005). Older people circulate through several family members' house in few situations. When it happens, it is primarily the home of other children, and the frequency of exchange, in most cases, monthly. These results do not seem to corroborate other studies, which state that the rotation system is more visible in the southern European countries, Portugal and Spain (Martin, 2005). However, it is believed the decrease in turnover in the current socio-economic context, urbanization, migration; decrease the number of children and housing characteristics (Martin, 2005).

The reason that mostly led to this situation was the elderly disease. The duty or obligation, such as love and affection, are not evident here rather than what was found in other studies (Imaginário, 2004; Veríssimo, 2004).

The study allowed us to conclude that major changes or difficulties experienced by these families fall mainly on rest and leisure activities, daily organization of family and economic difficulties. Imaginário (2004) confirms that the families of the dependent elderly mentioned that the socio-economic responsibility get worse by caring these seniors, for the economic overload and constraints of the family's social life, so it is evident the decrease of leisure, from family life and with friends, and holiday deprivation. Also according to the author, the familiar routines are altered, the level of the rest, relaxation, employment and meals. The restriction of social life and leisure of caregivers is also emphasized by Lage (2005) and Martins et al. (2014), the time is very scarce, and are among the main negative consequences, both for health physical and mental caregiver, inherent in providing care for the elderly. Brito (2002) and Martin (2005) found similar findings. Marques, Teixeira and Souza (2012) reinforce with their study the fact that caring dependent family members leads to changes in their personal, social, professional, physical and emotional lives, but they like to do it.

Most of these caregivers does not share the responsibility of care with other elements, noting that still they do not feel this need. When they do, they usually look for their spouse. Other studies also indicate that the majority of family care by themselves, without the help of others (Brito, 2002; Lage, 2005; Sequeira, 2007) and, when it exists, it comes from close relatives (Sequeira, 2007). However, the aid and support in providing care can contribute to a better quality of life of the caregiver (Brito, 2002; Lage, 2005; Sequeira, 2007).

In this research, according to the perception of respondents, their physical and mental health was not affected or was unaffected by the fact that care for the elderly. Most of the studies indicate that family caregivers are at risk of aggravating their physical and mental health conditions; however, it is necessary to note that they focus mainly on family caregivers of

dependent elderly. Sequeira (2007) found that most caregivers had health complaints, and caregivers of elderly without dementia are more sensitive to physical complaints and caregivers of seniors with dementia are more sensitive to psychic complaints. Although most caregivers have a reasonable perception of their health status, in general, they considered that the same has been deteriorated because they care a dependent elderly. On the other hand, time can lead to deterioration in the general condition of the dependent elderly and to a growing number and complexity of care, resulting in increased overhead for primary care providers and a perception of their health status and quality lower life (Salgueiro, 2008).

Most of these caregivers are supported by community formal institutions, mainly health and social, with the aid or care, health care (nurses and doctors), highlighting the nursing care and even economic aid. Imaginário (2004) surmised the narratives of caregivers that their main needs were attached with the help of another (aid under the tasks and emotional), helps health services (in terms of information, care and clinical material) technical, economic aid and be healthy. Lage (2005) further distinguishes the different care for men and women. Women provides more the emotional support and instrumental activities. Women fit the personal care and household chores, while men are more geared towards the elderly transportation and money management.

The institutional support provided by caregivers was considered as sufficient or appropriate. This seems to be positive because, according Sequeira (2007), satisfaction with social support, which includes family support, friends and institutions, promotes health, well-being and quality of life.

According to Lage (2005), by thinking the family goes beyond guiding and expect cooperation of the same in the home context, this should be considered an ally in maintaining the health and recovery of members, thus taking an active role in decision-making.

CONCLUSION

The issues of demographic aging have gained representation in the world due to the progressive and rather sharp increase in the elderly population, especially the elderly, a result of the substantial increase in life expectancy.

In relation to the demographic aging occurred profound social and family changes in recent decades, which affected the structure and composition of families, associated with greater female participation in the labor market of very high concern with the family

support that seniors will receive. The study results indicate that when the elderly people are ill, they look for asking support, especially to the female element.

The Government must recognize the family as an important source of support and care for their elderly relatives. Care for the older must then be designed in a more dynamic way, enjoying family support, which allows to both those who care and those who are cared to have quality of life.

The growing aging of population leads to increased chronic and disabling conditions, in some situations with a high degree of dependence, leading, especially at older ages, the need for family, social and health support. The implemented measures shall meet the needs of seniors and their families, focusing on the adequacy of health services and social support to new social and family realities. It would be interesting to be a computerized registration and date of informal caregivers, which makes it easier to care for those who care, in evaluating their problems/needs and overload, so that the supports are consistent with the care needs of the same.

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