ORIGINAL ARTICLE

Profile of the caregiver of dependent elderly family members in a home environment in the City of Porto, Portugal*

PERFIL DO FAMILIAR CUIDADOR DE IDOSO FRAGILIZADO EM CONVÍVIO DOMÉSTICO DA GRANDE REGIÃO DO PORTO, PORTUGAL

PERFIL DEL FAMILIAR CUIDADOR DE ANCIANO FRAGILIZADO EN CONVIVENCIA DOMÉSTICA EN LA GRAN REGIÓN DE PORTO, PORTUGAL

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ABSTRACT

This descriptive research aims to identify the profile of the family caregiver using the World Health Organization's QPFC and WHOQOL-Bref (instrument application methods) in a sample of 120 family caregivers of dependent elderly patients who represented the population of three Healthcare Centers in the area of the Great Porto, Portugal. Data were collected in the period between January 2005 and March 2005. Results indicated that female caregivers with 55 years of average age, who had other family care giving duties besides caring for the elderly family member, were the majority. The circumstances surrounding care giving, in the perspective of the elderly patient and the other family demands, generated negative consequences to the caregiver's life and health. However, at the same time, caregivers expressed positive perceptions and rewarding feelings when caring for the elderly family member. In a nutshell, it is essential for nurses to consider the binomial caregiver and dependent elderly patient, since both demand special healthcare attention from healthcare services.

KEY WORDS

Aged.
Caregivers.
Family.
Quality of life.
Nursing.

RESUMO

Estudo descritivo com o objetivo de caracterizar o perfil do familiar cuidador, cujo método foi a aplicação dos instrumentos QPFC e WHOQOL-Bref da OMS a uma amostra de 120 familiares cuidadores de idosos dependentes, representantes da população referida de três Centros de Saúde da Região do Porto, Portugal. Os dados foram coletados durante o período de 01/2005 a 03/2005. Destacou-se, como cuidador principal, a mulher na idade em torno de 55 anos, que tem aos seus encargos, além do idoso, outros dependentes da família. As circunstâncias de cuidado, sejam pelas necessidades do idoso, ou requerimentos familiares, impunham conseqüências negativas à vida e à saúde. Contudo, ao mesmo tempo, esses cuidadores manifestavam suas percepções e sentimentos positivos da sensação confortadora, da dignificação de suas vidas, ao assumirem o papel de cuidador do idoso. Em conclusão, como enfermeiros, é essencial considerar o binômio cuidador e idoso dependente, pois exige atenção especial de cuidados da vida e saúde por parte dos serviços de saúde.

DESCRITORES

Idoso.
Cuidadores.
Família.
Qualidade de vida.
Enfermagem.

RESUMEN

Estudio descriptivo con el objetivo de caracterizar el perfil del familiar cuidador y cuyo método fue la aplicación de los instrumentos: QPFC e WHOQOL-Bref de la OMS a una muestra de 120 familiares cuidadores de ancianos dependientes, representantes de la población referida de tres Centros de Salud de la Región de Porto, Portugal. Los datos fueron recolectados durante el periodo de 01/2005 - 03/2005. Se destacó como cuidador principal la mujer con edad en torno de 55 años, que tiene a su cargo, además del anciano, otros dependientes de la familia. Las circunstancias del cuidado sean por las necesidades del anciano, o por los requerimientos familiares, imponían consecuencias negativas a la vida y salud, sin embargo, al mismo tiempo esos cuidadores manifestaban percepciones y sentimientos positivos de sensación confortadora de dignificación de sus vidas al asumir el papel de cuidador del anciano. En conclusión, como enfermeros es esencial considerar el binomio cuidador y anciano dependiente, ya que exige atención especial de cuidados de la vida y salud por parte de los servicios de salud.

DESCRIPTORES

Anciano.
Cuidadores.
Familia.
Calidad de vida.
Enfermería.

Extracted from the research "Perfil da família cuidadora de idoso doente/fragilizado de diferentes contextos sócio-culturais", 2003.

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INTRODUCTION

In most countries, the care given to the elderly has always been performed by women, and most research demonstrates that caretakers are, mainly, wives, daughters and granddaughters[1-3]. This fact can be explained since, in the past, most women did not have roles outside their home, which justified their availability to care for family members. However, this reality has been changing due to women's social insertion, evidenced by their progressive participation in the working market. Recent studies show that caretakers are usually living with the elderly. They are married and, for this reason, add the activity of taking care of the elderly to their domestic activities as mothers, wives and grandmothers, among other roles. The household work is increased, generating an overload in many areas of life, whether social, physical, emotional or spiritual, contributing to their lack of care for themselves, and compromising their health in general[2-6].

There are many reasons that compel women to become the main caretaker. The following reasons stand out: the moral obligation based on cultural and religious aspects; the condition of being a spouse; the absence of other people to perform the role of caretaker, which forces the caretaker to assume this role not as an option, but due to the circumstances; and financial difficulties, as when the unemployed daughters take care of their parents for living[6-7].

One of the aspects that most affects the caretaker families is the financial difficulty experienced by the poorer members of the population. Many caretakers are unemployed and survive due to the resources provided by the elderly's retirement income. In many cases, these resources are only sufficient to provide for the basic needs of the elderly[5]. Studies also show that there are a significant difficulties involved in caring for the elderly, especially in dementia cases, where the elderly require special care and expose the caretaker to prolonged stress. In those cases, besides needing specific training to deal with the situation caring for another person with special needs, the caretakers need social support to sustain their own health and to be able to take care of themselves. When this support is not available, caretakers are exposed to the risk of becoming ill themselves, a risk that is not generated due to the task of caring, but is a result of the overload to which they are exposed[7-9].

One of the aspects that most affects the caretaker families is the financial difficulty experienced by the poorer members of the population.

Although recent literature points out the multiple features of the sick/fragile elderly caretaker family member within their domestic living situation, there is still the need for gathering more knowledge, considering that these features can present different aspects according to different socio-cultural contexts, and also according to the changes that occur in the family dynamics scope. For this reason, this multicentre research is justified. Its purpose was to learn about the profile of the fragile elderly caretaker family member, under different geographic contexts, as a multi-institutional effort.

STUDY AIM

The aim of this study was to identify the profile of the fragile elderly caretaker family member within their domestic living situation, in the Great Region of Porto, Portugal.

METHOD

This present study holds the purpose of presenting the profile of the elderly caretaker family member in the socio-cultural context of the Great Region of Porto, Portugal. It represents a portion of the general report of a research replicated in five centers: Florianópolis, SC; Jequié, BA; Passo Fundo, RS; Rosário, Ar[9].

Porto is a city in the northern region of Portugal that contains a population that represents, according to INE (National Statistics Institute of Portugal) data from 2004, 35.4% of the total population of the country; in other words, 9,869,343 inhabitants. The population of the Great Region of Porto is 263,131 inhabitants, including the elderly population of 65 years old and above totaling 47,192, where 17,149 (36.3%) are men and 30,043 (63.7%) are women.

This study constitutes a descriptive-exploratory research of an evaluating-diagnostic nature, where the caretaker family member of the elderly person, the object of this study, is the caretaker of a sufferer of any chronic disease, usually with a co-morbid condition (poly-pathology), and who is fragile due to the condition and the aging process, which renders them incapable of caring for themselves and dependent for daily care. Data were collected in the period between 01/2005 and 03/2005 and were gathered through the application of a Questionnaire on the Profile of the Caretaker Family Member (*QPFC*), which was specially created for the project[10]. This questionnaire was divided into three parts. The first part comprised the identification of the main caretaker family member, highlighting their socio-demographic variables, health conditions and quality of life; the second part was comprised of a quality of life evaluation of the caretaker, in which the WHOQOL-Brief from the WHO[11-12] application was included.

The *QPFC* was elaborated by the research team working with the Study Group on Elderly Peoples' Health at the Federal University of Santa Catarina Nursing Graduate Program (GESPI/PEN/UFSC) and subjected to many tests under different application contexts. Its elaboration was based on the experience of the team and especially on the *Encuesta a Personas Cuidadoras* instrument nationally applied by the *Centro de Investigaciones Sociológicas* (Center of Sociological Investigations) at *Instituto de Mayores y Servicios Sociales* (Instituto for the elderly and social services) in Spain[13].

The sample was intentional and was comprised of 120 caretaker family members of the elderly, identified by three

health centers of the Great Region of Porto. Inclusion criteria were defined as follows: caretakers with elderly family members who were 65 years of age or older; b) the cared-for elderly should be fragile/ill (considering the dependency condition of the care); c) the main caretaker should be identified by the family as the person responsible for the elder family member, and should provide most of the care required.

Research participants, after they were selected and informed about the study, and after they voluntarily agreed to participate and collaborate, signed a Free and Informed Consent Form.

The project, in its general conception for the application in many centers, entitled: *Profile of the caretaker of the fragile/sick elderly family member from different socio-cultural contexts*, under protocol No. 103/02, was approved by the UFSC Ethics Committee for Research involving Human Beings (in agreement with Regulation 196/ of the Brazilian National Health Council).

RESULTS AND DISCUSSION

Caretaker family members: featuring, health condition and quality of life

The sample, mostly composed of married women, on average 55 years old and with reduced educational levels, apart from the caretaker role, hold the role of taking care of household tasks as mothers, according to what is shown in Table 1.

Table 1 - Distribution of the socio-demographic features, health perception and quality of life, and the sick/fragile elder caretaker family members conditions in the context of the Great Region of Porto, Portugal - 2005

Features of the caretaker family member	Frequency
Age (average)	55 years old
Gender: M/F	16/84%
Marital Status	
Married	78%
Single/Separated	17%
Widow	5%
Education level	
Illiterate	5%
Primary level (up to 4 years)	95%
Occupation/working outside the home	
Yes	25%
Health self-appreciation	
Great/Good	27%
Average	58%
Bad/poor	15%
Quality of life (score)	
Satisfied/very satisfied	45%
Moderately satisfied	42%
Unsatisfied	13%
Condition of the single caretaker	66%
Caretaking period of greater than 3 years to more than 10 years	62%
Caring for other dependents	22%
Living with the elderly person under care	69%

Similar to other studies[3-4,7,9,13-14] the majority of caretakers were married, followed by divorced/separated or single, and a small portion were widows, generally women and most of the time caretakers of their own elderly spouse. Regarding occupation, many caretakers did not perform any extra-domestic activity and dedicated themselves fully to the care of the elderly and other members of the family, in addition to domestic tasks. Parallel to that, 25% engaged in professional activities in addition to the care of the elderly family member. Also, according to other research findings, many caretakers were forced to leave their job or reduce their working hours in order to take care of the elderly family member when this level of permanent dedication was required (Table 2).

When asked about their health condition, caretakers mentioned hypertension and other cardiac disorders, followed by cumulative trauma and mental disorders. The perception of their own current health condition as good or average was observed in the majority of cases. However, when they were asked to compare their condition to five years ago, almost half of the sample mentioned that their condition had worsened.

Similar to the subjective perception of health, quality of life was indicated as being between average and good in the majority of participants. Few stated having a poor quality of life, a fact coinciding with the answers regarding the satisfaction and dignifying sensation of being a caretaker, despite living in a stressful, tiresome situation, lacking time for pleasure and self-care.

As for more specific Brazilian research [2-6,14-16], also regarding the profile of elderly caretakers from CIS/IMSERSO[13] in Spain, data still demonstrate that elderly caretakers are predominantly middle-aged women. As a matter fact, they were the closest family members who generally assumed the caretaking tasks. They were mostly daughters, followed by spouses. A crescent participation of men, at different ages, was observed as in this study, where spouses, sons and grandsons are featured. The inter-generational acquaintanceship seems to show a positive relationship as family members assume the role of secondary caretakers, minimizing the stress- generating situation on the main caretaker.

Caretaker family members: care condition

Regarding care delivery, the study demonstrated that most caretakers (73%) performed that task permanently; in other words, they were fully dedicated to the care of the elderly family member, investing five or more hours a day in the activity, helping with walking and transferring, bathing, toileting activities, dealing with urinary incontinence, dressing and undressing, feeding, and many other tasks.

Similar to other studies regarding caretakers, this study also revealed that the elderly care process in the domestic context can generate limitations on the daily life of the care-

taker, culminating in consequent risks to their health and welfare. This can be observed through their answers in Table 2.

Table 2 - Frequency of consequences originating from the task of taking care of the elderly, according to elderly caretakers in the great Region of Porto, Portugal - 2005

Consequences	Frequency (%)
Always tired	61
Worsened health condition	46
Having to reduce outside working hours	46
Not able to take vacations	44
Not having time to spend with friends	41
Feeling stressed/depressed	41
Having no time for self-care	38
Increase in economic problems	32
Not able to work outside the home	18
Having to leave their job	17
Not having consequences affecting their life	15
Having conflicts with the spouse	9
Leisure time reduced	3

Note: The percentage of each item corresponds to 100% of the sample.

The significant number of caretakers permanently dedicated to the task, revealed in this study, confirms data from the same research within other contexts[7-9]. Taking care of an elderly person for a prolonged period of time (34% have been caretakers for more than 3 years) requires constant exposure of caretakers to the risk of illness, especially for those who are *single caretakers*, assuming full responsibility. Regarding women, they accumulate many roles, such as mother, wife and caretaker of other dependents. This overload compromises self-care. This fact is illustrated in some answers from Table 2, such as not being able to enjoy vacations, leisure time, not taking care of their health and life, as well as the occurrence of marital issues.

The elderly cared by these family members had diseases such as: hypertension, followed by diabetes mellitus, cardiovascular disorders and stroke consequences, cumulative trauma disorders and cancer. Most of them have co-morbid conditions.

Dealing with these care circumstances within the most diverse family life dynamics, willingness and solidarity in assuming the care of the elderly was not enough for the caretaker. Therefore, it is crucial for the health institutions to provide support and basic orientation for the care, according to the specificities of each situation.

Caretaker family member: Relationship with the cared-for elderly

Regarding habitual elderly behavior and the care necessary for Daily Life Activities as events that may or may not induce strain on their caretakers, this fact was researched and the answers are presented in Tables 3 and 4.

Table 3 - Distribution of common elderly behavior and their respective disturbance or annoyance reactions produced in family member caretakers in the context of the Great Region of Porto, Portugal - 2005

Elderly behavior	Frequency %	Disturbance %
Sleep alterations	51	21
Repeating the same stories continuously	45	20
Soiling clothes with urine and feces	41	18
Complains about the situation all the time	37	9
Forget routines such as taking medication	37	15
Cannot find things	34	9
Gathers useless things	34	14
Always crying	29	14
Does not like to take baths	28	9
Wants to stay in their room	25	8

Note: The percentage of each item corresponds to 100% of the sample.

Table 4 - Distribution of the elderly daily life activities which required the assistance of a family member caretaker and their respective reactions to annoyance and disturbance, in the context of the great Region of Porto, Portugal - 2005

Help required in the daily life of the elderly	Frequency %	Disturbance %
For walking/transferring from one place to another	69	15
To take a shower	71	14
To get dressed/undressed	78	9
To take care of finances	74	9
To assist with feeding	76	6
To prepare food	71	5
To administer medication	71	5
To clean the house	71	3

Note: The percentage of each item corresponds to 100% of the sample.

According to Table 3, the common behaviors presented by the elderly, whether they be sleep alterations, repetitive behaviors or urinary and fecal incontinence requiring a constant change of clothes in relatively high frequency (41%), there was a surprising and relatively low frequency of answers from caretakers, demonstrating that they were not upset or annoyed by such behavior as they cared for their elderly. Although this answer apparently shows that caretakers are accustomed to taking care of the elderly, it raises some questions; for instance, regarding the behavior of not wanting to participate in hygiene, does not being annoyed by the behavior mean that the caretaker is an accessory to the situation, being negligent in care? Does the real caring and needed patience lay in convincing the elderly to participate in effective and necessary care? These questions and others that are instigated by observing the data in Table 4 require deep qualitative research to cap-

ture the shades of living the caretaking process assumes. In Table 4 the daily life activities of the elderly who required the assistance of a caretaker can be found.

Although the need for assistance or providing direct and intimate personal care are frequent in the elderly, caretakers answers indicating that they are not annoyed or distressed by providing this care causes us to assume that these caretakers hold a special calling for taking care of the elderly. However, the following deserve to be explored further : could not being annoyed by needing to take the elderly periodically to the restroom or to give them baths constitute negligence on the part of the caretaker when he/she is available to perform the task only when it brings him/her pleasure? As a further example, when transporting the elderly by bus to take them to a medical consultation or to rehabilitation, could it be inadequate for the health of the elderly if they perform the task only when external resources are available? These speculations deserve to be examined under the complex dynamics of family care surrounded by this precarious institutional and community support network for the poorer populations.

Regarding the identity of the caretaker providing care activities for the elderly, the data presented in Table 5 reveal that many regard this care as something that dignifies the person as someone who is accomplishing a moral and religious duty, and many are satisfied by the elderly manifestations of gratitude and by the acknowledgement of the family and community. It is important to highlight that the same caretakers assume the ambiguous satisfaction sensation of an accomplishment at the same time that they realize the distress, stress and worsened health.

Table 5 - Distribution of the affirmations which caretakers identified regarding the performed tasks in the care for the elderly, in the context of the Great Region of Porto, Portugal - 2005

Reasons for the care	Frequency %
I consider it a moral obligation	41
There is no remedy but caring	28
The cared-for person is very thankful	23
My family supports and values this role	20
It is something that dignifies me as a person	15
I find support in my religious convictions	12
People from my outside circle think that I should not perform this sacrifice	3

Note: The percentage of each item corresponds to 100% of the sample.

These initial findings deserve explorative studies, as cultural research[15] aimed at the caretaker woman who is not valued by the community with stable ethnic features has not been commonly performed. There is also another study[16] that describes the positive cognitive evaluations of the dependent elderly caretaker, which highlights the psychosocial benefits of the care.

Nevertheless, most studies continue to demonstrate that the care for the elderly depressively interferes in the life of the caretaker. This study presents some positive aspects that should be explored with a view to contributing to the search for better self-esteem and, consequently, better quality of life, health and welfare.

Through this perspective, acknowledging the profile of dependent elderly caretakers largely contributes to providing the essential resources for local services: social and health[17], in re-planning the programs guided towards family service, including those that have elderly members and the reconstruction of appropriate caretaking technologies for the different situations within family care.

CONCLUSION AND IMPLICATIONS

Globally we can assume the profile of the family member caretaker of the fragile elderly found in this study in the community of the Great Region of Porto, PT, as follows:

- Women, of an average age of 55 years old, married, with a reduced educational level and most of them living in the same house as the elderly;
- Daughters or spouses of the dependent elderly;
- With multiple tasks to perform; in addition to taking care of the elderly with minimum support, and in the majority for a period between 3 to 6 years, they are responsible for other domestic duties;
- When evaluating their health condition, on average, their health tends to worsen, requiring health care for themselves;
- Presenting difficulties in dealing with some behavior alterations of the elderly family member, namely referring to sleep disturbance, memory and humor;
- Presenting ambiguous feelings of being tired, stressed and unsatisfied because they cannot take care of themselves, parallel to the feeling of accomplishment, dignity and gratitude.

These findings show the relevance of dynamic differences in taking care of the fragile elderly which can, eventually, positively influence or not the welfare of both the person under care and the caretaker. Summarizing, as nurses it is essential to consider that the family binomial of caretaker/dependent elderly deserves social and health attention in a specific way, by the social and health services.

On the other hand, although it presents relevant features to stimulate public policies - social and health - the present profile of the dependent elderly caretaker still requires further studies, mainly qualitative, with a view to capturing the numerous shades of the caretaker/elderly relationship process within the complex dynamics of family care.

REFERENCES

1. Glozman JM Quality of life of caregivers. Neuropsichol Rev. 2004;14(4):183-95.

2. Diogo MJDE, Ceolim MF, Cintra FA. Orientações para idosas que cuidam de idosos no domicílio. Rev Esc Enferm USP. 2005;39 (1):97-102.

3. Karsch UM. Idosos dependentes: famílias e cuidadores. Cad Saúde Pública. 2003;19(3):861-66.

4. Sequeira C. Cuidar de idosos dependentes. Coimbra, PT: Quarteto; 2007.

5. Alvarez AM. Tendo que cuidar: a vivência do idoso e de sua família cuidadora no processo de cuidar e ser cuidado em contexto domiciliar [tese]. Florianópolis: Programa de Pós-Graduação em Enfermagem, Universidade Federal de Santa Catarina; 2001.

6. Santos SMA. Idosos, família e cultura: um estudo sobre a construção do papel do cuidador. Campinas: Alínea; 2003.

7. Gonçalves LHT, Alvarez AM, Santos SMA, Spricigo JS, Portella MR, Scortegagna H, et al. El perfil de la família cuidadora del anciano enfermo/debilitado en los contextos sócio-culturales de Florianópolis, SC y Passo Fundo, RS. Pan Am Enferm. 2005;3 (2):185-94.

8. Silva LWS, Gonçalves LHT, Alvarez AM, Sena ELS, Vicente FR. Perfil da família cuidadora de idoso doente/fragilizado do contexto sociocultural de Florianópolis, SC. Texto Contexto Enferm. 2006;15(4):570-77.

9. Gonçalves LHT, Santos AS, Costa MA, Rossi CL, Portella MR. Profile of the family caregiver for a frail elderly relative in the domestic environment at the five sociocultual contexts of Florianópolis/SC, Jequié/BA, Passo Fundo/RS, Rosario/Ar, and Porto/Pt In: Program of 18th Congress of The International Association of Gerontology; 2005 jun 28-30; Rio de Janeiro, BR [CD-ROM]. Rio de Janeiro: SBGG; 2005. [Abstract].

10. Fratoni MM, Nassar SM, Gonçalves LHT. Questionário de perfil da família cuidadora (QPFC). Software computacional. Florianópolis: GESPI/UFSC; 2004.

11. World Health Organization (WHO). WHOQOL Gr. Measuring quality of life: the development of the World Health Organisation Quality of Life Instrument. Geneva; 1993.

12. Fleck MPA, coordenador. Versão em português do instrumento de avaliação de qualidade de vida WHOQOL; 1998 [texto na Internet]. [citado 2006 fev. 27]. Disponível em: http://www.ufrgs.br/psiq/whoqol84.html

13. Espanha. Ministério de Trabajo y Asuntos Sociales de España. Cuidados en la vejez: el apoyo informal. Madrid: CIS/IMSERSO; 1999.

14. Giacomin KC, Uchoa E, Lima-Costa MFF. Projeto Bambuí: a experiência do cuidado domiciliário por esposas de idosos dependentes. Cad Saúde Pública. 2005;21(5):1509-18.

15. Budó MLD. Cuidando e sendo cuidado: um modelo cultural de suporte à saúde em comunidade rural de descendentes de imigrantes italianos [dissertação]. Santa Maria: Pós-Graduação em Extensão Rural, Universidade Federal de Santa Maria; 1994.

16. Sommerhalder C. Significados associados a tarefa de cuidar de idosos de alta dependência no contexto família [dissertação]. Campinas: Faculdade de Educação, Universidade Estadual de Campinas; 2001.

17. Rodrigues SLA, Watanabe HAW, Derntl AM. A saúde de idosos que cuidam de idosos. Rev Esc Enferm USP. 2006;40 (4):493-500.

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