QUALITY OF LIFE OF CAREGIVERS OF ELDERLY PEOPLE LINKED TO A HOME CARE PROGRAM

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ABSTRACT

Objective: to verify whether the monitoring in a home care program has changed the quality of life (QOL) and the burden of caregivers of elderly people. Method: intervention study comparing the QOL scores and burden of 21 caregivers of elderly patients before and four months after their inclusion in a home care program, from July 2008 to January 2011. The data were analyzed in the Statistical Package for Social Sciences (SPSS) 18.0 program and the significance level adopted was 5% (p ≤ 0.05). Results: the better the perception of QOL in the domains psychologic and environment, the lower the assessed burden of the caregiver. Statistically significant changes were not identified in the overload and in the QOL at the time of entry in the program and four months later. Conclusions: this study expands the understanding of nurses about caregivers vulnerabilities and identifies the need to increase home care to them and to the elderly. Descriptors: Caregivers; Aged; Home Nursing; Home Care Services; Quality of Life.

RESUMO

Objetivo: verificar se o acompanhamento em um programa de atendimento domiciliar modificou a Qualidade de Vida (QV) e a sobrecarga de cuidadores de idosos. Método: estudo de intervenção que comparou os escores de QV e sobrecarga de 21 cuidadores de idosos, antes e quatro meses após a inclusão desses em um programa de atenção domiciliar, no período de julho de 2008 a janeiro de 2011. Os dados foram analisados no programa Statistical Package for the Social Sciences (SPSS) 18.0 e foi adotado o nível de significância de 5% (p≤0,05). Resultados: quanto melhor a percepção de QV nos domínios psicológico e meio ambiente, menor a sobrecarga avaliada pelo cuidador. Não foram identificadas alterações estatisticamente significantes da sobrecarga e na QV no momento do ingresso no programa e quatro meses após. Conclusões: o estudo amplia a compreensão dos enfermeiros sobre as vulnerabilidades dos cuidadores e identifica a necessidade de expandir estas modalidades de atenção. Descriptores: Cuidadores; Idoso; Assistência Domiciliar; Serviços de Assistência Domiciliar; Qualidade de Vida.

RESUMEN

Objetivo: verificar si el acompañamiento en un programa de atenci ón domiciliario modificó la Calidad de Vida (CV) y la sobrecarga de cuidadores de ancianos. Método: estudio de intervención que comparó la puntuación de CV y sobrecarga de 21 cuidadores de ancianos, antes y cuatro meses después de la inclusión de estos en un programa de atención domiciliaria, en el periodo de julio de 2008 a enero de 2011. Los datos fueron analizados en el programa Statistical Package for the Social Sciences (SPSS) 18.0 y fue adoptado el nivel de significancia de 5% (p<0,05). Resultados: cuanto mejor percepción de CV en los dominios psicológico y medio ambiente, menor la sobrecarga evaluada por el cuidador. No fueron identificadas alteraciones estadisticamente significativas de la sobrecarga y en la CV en el momento del ingreso en el programa y cuatro meses después. Conclusiones: el estudio amplía la comprensión de los enfermeros sobre las vulnerabilidades de los cuidadores e identifica la necesidad de agrandar el atendimento domiciliario a estos y a los ancianos. Descriptores: Cuidadores; Anciano; Atención Domiciliaria de Salud; Servicios de Atención de Salud a Domicilio; Calidad de Vida.
INTRODUCTION

The Brazilian demographic and epidemiological transition and the consequent increase of the elderly population has required more attention, because besides being great users of health services, elderly people have higher rates of hospital admissions and increased time of stay in beds. Therefore, the care for the elderly is complex and requires team work.

One of care modalities that has demonstrated high impact in the international context to this age group is the Home Care (HC). In developing countries, it still has shortages, which causes that care is provided by an informal support system. In Brazil, the HC began to be discussed in the 90s. In 2002, Law No. 10,424 added the home care to the Health Law No. 8080 in the Unified Health System (SUS). Since then, public policies directed to the care of the elderly have included this modality of care as an alternative to better care of users and use of financial resources. Recently, Ordinance No. 2527 of 2011 redefined the HC, aiming to reorganize the work process of the teams that provide home care. However, despite the established policies, HC is still performed partially.

In 2002, in the city of Porto Alegre, the Homecare Program for Bedridden (PADA in Portuguese) was implanted in the Primary Health Care Service (PHCS) of the Health Center IAPI. This was an initiative to meet the needs of older adult users and their caregivers, since this service is located in one of the regions with the highest proportion of elderly in the city. The PADA has a multidisciplinary team of nurses, nursing assistants, physicians, psychologists, social workers and nutritionists, and serves on average 40 patients simultaneously. To join the PADA, the family makes a request in the PHCS and is interviewed by a nurse or social worker in the service. Later, a visit to the family’s home is performed to assess the need for home care. Inclusion criteria in the program are: user must live in the service’s coverage area, be unable to move up to the unit, and there must be a responsible caregiver. From this assessment, professional decide to include or not the user in the program and, if included, they propose a care plan.

At home, the elderly care is provided by a person who has or does not have family ties with the patient, and who aids in patient’s needs and in their activities of daily living. This person usually does not have any training in health area and receives no payment. When this person takes all or most of the care, they are called as primary caregiver.

Taking care of a dependent elderly may have consequences for the quality of life (QOL) of caregivers. This can be analyzed through the positive perspective, translated in well-being, and through the negative perspective, represented by work burden and stress. Burden can be understood as the effort dispensed in elderly care that negatively influences the caregiver’s way of life. The QOL in this study, is understood as “the individual's perception of his position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”.

Many Brazilian studies have been dedicated to assessing the elderly caregivers and point out that these have high levels of burden, recommending HC as an alternative to support the elderly, their caregivers and family members, aiming to improved QOL. Intervention studies assessing the impact of HC to the elderly have been carried out in the international context, having as outcomes the QOL, the functional capacity, hospitalization rates and costs. There were no national studies assessing outcomes for caregivers. Assessing the caregiver beyond the tasks performed or their characterization can assist in guiding HC services, supporting the planning of their actions in order to qualify it.

OBJECTIVES

- Characterizing the primary caregivers of elderly patients seen by PADA and the care provided by them;
- Verifying whether the monitoring in HC program has modified the QOL and the burden on caregivers;
- Verifying the association between QOL domains and their burden score.

METHODS

This is an before and after an intervention study. Data was collected from July 2008 to January 2011 with the primary caregivers of elderly patients seen in PADA, who met the research inclusion criteria: self-defining as the primary caregiver of person aged 60 years or more, the elderly having been included in the PADA, keeping in the program during the data collection period and participating in the first and second interviews.

The research involved two stages. First, the caregivers were invited to participate in the study when requesting the program inclusion. Three instruments were applied: (1) a questionnaire on sociodemographic and health...
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data, and about the care provided to the elderly person, (2) the abbreviated instrument for assessing QOL of the World Health Organization (WHO), WHOQOL-BREF; (3) the Zarit Burden Interview Scale (ZBI) validated by Scazuca to assess caregivers’ burden.

The WHOQOL-BREF is an abbreviated version of WHOQOL-100 and consists of 26 questions. Two of which focus on how the individual evaluates their QOL and how satisfied they are with their health, and 24 questions divided into four domains: physical, psychological, social relationships and environment. The instrument questions were formulated by using a Likert type responses scale with five levels, with a scale of intensity (nothing - extremely), capacity (nothing - completely), frequency (never - always) and evaluation (very dissatisfied - very satisfied; very bad - very good). The higher the score in each domain (0 to 100), the better the perception of QOL. The instrument showed adequate characteristics of internal consistency, discriminant validity, criterion validity, concurrent validity and test-retest reliability for use in Brazil.

The ZBI is composed of 22 items that assess caregiver’s burden in their social and financial life, and physical and emotional well-being. The responses are recorded in a frequency scale from zero (never) to four (always) points, which shows a linear score from 0 to 88 points, and the higher the total score, the greater the burden.

The second stage of the research took place four months after the first interview, when the same instruments described above were applied again. The choice for this time interval was set considering the program team experience that evaluated as appropriate this intervention time. To meet the rigorous study and reduce losses, the second interview was conducted with a flexibility of 15 days before or after the scheduled date.

The sample size was calculated in the Programs for Epidemiologists (PEPI) version 4.0. It was adopted a 95% confidence level and a power of 85% with effect size of a standard deviation (SD) between the evaluated times. It was calculated that the study should have a minimum of 19 subjects.

A total of 50 caregivers were identified consecutively, when requesting the inclusion in the program. Of these, 10 users did not meet the criteria for inclusion in PADA; nine died before completing four months in the program; four were discharged from the program in the course of data collection; two refused to continue the study and four caregivers were not found for the second interview after three attempts at different times and days of the week, including Saturdays and Sundays. Thus, the study sample included 21 caregivers. The interviews were conducted by scientific initiation scholars, previously trained by researchers.

Data were analyzed using the Statistical Package for the Social Sciences (SPSS) 18.0 and it was adopted the significance level of 5% (p ≤ 0.05). Quantitative variables were expressed as mean and standard deviation (SD). The qualitative variables were described by absolute and relative frequencies. The Student’s t-test was used for paired samples for comparison of QOL (WHOQOL-BREF) and burden before and after inclusion in the PADA. For associations between variables, it was used the Pearson’s linear correlation test.

The study was approved by the Ethics Committee of the Municipal Secretariat of Porto Alegre / RS, under No 001.029434.08.4. All caregivers signed the Informed Consent Form and the research was conducted in accordance with Resolution no. 466/12 of the National Health Council.

RESULTS

Among the 21 caregivers, 71.4% were female and the average age was 60.4 years old (SD 11.64 years), ranging between 44 and 83 years old, and 42.9% of caregivers were aged 60 or more. The average age of the elderly was 81.7 years old (SD 9.1 years). Much of the respondents (57.1%) were seniors’ daughters. As for education, there was a higher proportion (61.9%) of caregivers with more than nine years of study, with a mean time of 9.2 years (SD 4.6 years). Regarding the health status of caregivers, the most mentioned diseases were arthropathies (61.9%), followed by hypertension (SAH) (19%).

The average time that the caregiver had been providing aid to the elderly was 4.64 years (SD 4.5 years), ranging from one month to 15 years. Most (95.2%) exercised this activity in full-time, all lived with the elderly and 42.9% did not receive help to perform care.

The main reasons given by the caregivers to take responsibility for the elderly person were for dignity (76.2%) and for being a moral obligation (61.9%). Among the consequences arising from the task of taking care, there was highlight for always feeling tired (81%), reduced leisure time (81%) and not having time to take care of themselves (71.4%).
All seniors needed help to perform some activities of daily living (ADLs), of which 95.2% needed help for dressing; 90.5% for locomotion / moving from bed to chair; 85.7% for the care of their appearance, bathing and cleaning the house; 76.2% to prepare meals; 71.4% for eating; 57.1% for changing diapers and 52.4% to use the bathroom.

Regarding the QOL, Table 1 shows the scores of the WHOQOL - BREF before and after four months of inclusion in the PADA. There was improvement in the scores of the physical and environmental domains and in the answer to the question of overall QOL of the instrument, but without statistical significance. The overall QOL was the score with the highest increase when comparing the two periods of research.

Table 1. Comparison of QOL scores of caregivers before and after four months of inclusion in the PADA, Porto Alegre, 2011. (n=21)

<table>
<thead>
<tr>
<th>Domains</th>
<th>Before Mean ± SD</th>
<th>After Mean ± SD</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>64.5 ± 16.2</td>
<td>68.4 ± 15.2</td>
<td>0.154</td>
</tr>
<tr>
<td>Psychological</td>
<td>60.7 ± 17.8</td>
<td>60.7 ± 19.2</td>
<td>1.000</td>
</tr>
<tr>
<td>Social</td>
<td>58.3 ± 19.4</td>
<td>59.1 ± 20.1</td>
<td>0.861</td>
</tr>
<tr>
<td>Environment</td>
<td>56.6 ± 16.2</td>
<td>60.7 ± 13.7</td>
<td>0.199</td>
</tr>
<tr>
<td>Overall</td>
<td>51.2 ± 22.7</td>
<td>58.9 ± 21.7</td>
<td>0.131</td>
</tr>
</tbody>
</table>

Regarding to caregivers’ burden, there was no significant statistical change in the overall score before and after four months of monitoring in the PADA. The average burden, before inclusion in the PADA, was 35.48 (SD 16.6) and after, 36.6 (SD 12.8) p = 0.409.

There was a statistically significant inverse association between the change of burden scores with the change of scores in the environment domain (r = -0.611; p = 0.003) and in the psychological domain (r = -0.440; p = 0.046) of the WHOQOL - BREF, that is, the better the QOL perceptions in these areas, the lower burden.

**DISCUSSION**

Corroborating the results of other studies, most caregivers were women, daughters, living with the elderly and providing full-time care, which reinforces the image of women as having skills that allow providing care as an extension of house chores.8,9,15

The average age of caregivers (60.4 years old) was higher when compared to other studies on the theme.9,16 It is also known that being an elderly caregiver predisposes to various diseases. This is due to the efforts made, which often leads to decreased self-care that, associated with the natural aging process, weakens the caregiver. This is a situation that deserves attention of researchers and practitioners, as it tends to become increasingly common with increasing longevity.10

As for education, low level of education is often cited in Brazilian literature,6 however, this investigation showed high level of education, related to social characteristics of the region, which could positively influence the care of the elderly, because it is assumed that the caregiver has a greater understanding of the guidelines provided by the home care team.

The percentage of arthropathies reported by caregivers, associated with old age, can be harmful to health. Study 13 showed that these diseases increase by 59% the chances of these group becoming dependent in ADLs. Among the analyzed sample, most did not receive help to provide care to the elderly, differing from that found in another study on the subject.16 The large number of caregivers with old age, deprived of help and providing full-time care raises doubts on whether these elderly people should or should not be taken care of at home.

Although HC is a practice that should be encouraged, in such a situation, it should be shared with other caregivers and support services that can meet the needs of the elderly and the caregiver.15 Caregivers need both help from other family members and also guidelines from health care team to deal with the issues associated with the older adults’ pathology, a fact that has been proved favorable to reduce burden.16 however, determining the reasons that led someone to be a caregiver is a complex task, especially in the context of children that are caregivers because it involves feelings of obligation and affection, as well as family counseling and a desire for reciprocity. In addition to the moral aspects, in Brazil, there is an established legal responsibility in the Elderly Law which delegates to the family the obligation to care for their elderly members.17-18

Being a caregiver brings important consequences as not having time to take care of oneself, always feeling tired and having reduced leisure time, which stood out in this study. These consequences contribute to
social isolation, since they imply a greater dedication to the elderly person, depriving the caregiver to maintain contacts and other social activities outside the home. This fact reinforces the need for inclusion of other types of care, such as Day Care Centers for the elderly, which aim to reduce the time spent on this task and provide the maintenance of social life and self-care.

Most of the PADA caregivers showed moderate levels of burden, resembling other studies. Among the factors that may have contributed to non-reduction of burden, there are: the need of great help of elderly participating in the PADA in carrying out ADLs, the care provided in full-time and the fact that all caregivers live with the elderly person, with reduced support from others in the informal network, characterizing a care provided continuously and possibly generating greater burden. One can also consider the average age of the elderly assisted, as older seniors require care that require more effort.

As for the QOL of caregivers, some studies have assessed it, however, none performed an evaluation before and after the monitoring HC programs. As for the association between burden and QOL, it was identified lower rate of burden associated with better perception of QOL in the environment and psychological domains, also found in other investigations, which can be attributed to the fact that PADA actions improve environmental conditions, encompassing the lack of need to carry the bedridden patient to health care service and the provision of information aimed at adapting the home, facilitating the provision of care.

The period of monitoring in the PADA may also have been short to detect positive changes in QOL and burden. Additionally, it was found that care had been provided on average for more than four years by caregivers who came to rely on this service in an already advanced stage of the elderly's dependency.

In addition to these issues, being the main actor responsible for the quality of care and the caregiver's care network.

There was no reduction in burden and no significant improvement in the QOL of caregivers, which can be attributed to the check that care was provided in full-time, to the high degree of assistance required by the elderly and to the old age of caregivers. It is important to consider that the average length of care was more than four years, so there is the need to assess the caregiver after longer time of follow-up in the program, so that a positive impact on QOL is detected. In addition, the improvement in QOL of caregivers because of the aid in ADLs contributes to the PADA assistance is not enough to reduce burden and to have an impact on the QOL. This refers to the possibility of this type of care be more effective for the caregiver in steps of less dependence of the elderly or that other forms of more intensive home care can be made available.

It is worrisome the number of old aged caregivers that help dependent elderly. The physical effort made to carry out this task, coupled with the biopsychosocial aging process, contributes to the onset and / or worsening of conditions and the deficit in the care of others and of oneself.

It is noteworthy that, despite the exercise of care generates stress and burden on caregivers, they often relate this assignment to positive feelings such as honor, dignity and social value. In this context, the benefits inherent in maintaining the health of the elderly in their homes require the strengthening of HC with the help of a multidisciplinary team, in which nursing must, in addition to assisting the elderly, support the caregiver and the family, as they are the main actors responsible for the quality of care given to the elderly.

Thus, delegating responsibilities to the family and providing therapeutic support to the elderly is not enough so that the HC is resolute, because the presence of a caregiver requires support to deal with changes in family dynamics required by the task of taking care. This calls for support alternatives such as support networks for caregivers, monitoring
and safety programs for the elderly, leisure and socializing centers, seeking to reduce the burden on caregivers with consequent improvement in QOL.

This study aimed to enable nurses working in primary care to broaden their understanding of the vulnerabilities of caregivers of bedridden elderly; it found that the HC can be an important formal care strategy to be started early and the need to increase home care to more dependent elderly and their caregivers.

The study was limited by the fact that the subjects search was linked to the inclusion of the elderly in the PADA, and the program stopped receiving new patients at several points along the data collection due to the great demand. Added to this, the large number of deaths during the collection, attributed to old age and severity of the health status of the elderly.

Longitudinal studies for longer time that evaluate these and other outcomes are needed in order to have greater understanding of issues related to the care and interaction between caregiver, the elderly person and staff.

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