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Introductory Note

Quality of life, human finitude and work overload for caregivers: an exploratory study

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ABSTRACT

This is a doctoral study developed as part of the Graduate Program in Nursing of Brasilia University.
Aim: to analyze the relationship between the perception of the quality of life and work overload, and their connection to human finitude and psychosocial implications in assisting patients in homecare.
Method: this is a descriptive and exploratory study, involving a cross sectional and qualitative approach, using semi-structured interviews and specific instruments to collect data. This took part between March and September 2013. The data will be analyzed using statistical software SPSS®, version 13.0, in addition to the use of topic content analysis.

Descriptors: Quality of Life; Caregivers; Home Care Service.

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PROBLEM SITUATION AND ITS SIGNIFICANCE

The evolution of continuous treatments for several chronic diseases results in a higher survival rates on the part of patients, and calls attention to the preoccupation with the quality of life of people and their relatives. Hospitalization, due to a lack of a definite cure, is considered inappropriate when it comes to treating chronic-degenerative diseases and, in many cases, it is seen as not being particularly beneficial to the patient. Home care has become a possibility as a means of merging the necessary healthcare and the family and the social network, in a healthy and safe environment.

In the face of terminal diseases, family members that have an affectionate bond with the patient may assume the role of home caregivers. However, many people are not normally prepared to perform this role which, despite its complexity, has to be added to the patient's daily routine(1). Depending on the time needed and the roles played by the home caregiver, this person is the one, directly or indirectly, who has the main individual responsibility for the patient. S/he may also have some financial support when acting in this position, which makes it a formal labor activity(2). The promotion of health and the support of family caregivers represents new challenges to the Brazilian health system. The terminology 'palliative care' defines a phenomenon that involves multiprofessional and multidimensional teams, with a focus in taking care of patients in the absence of therapeutic possibilities. The aim of such an approach is to promote the comfort and well-being of the patient and his/her family, as well as a reduction in negative symptoms. This can result in an improvement in the quality of life and can lead to a dignified process with regard to death(3).

The long home care involved with regard to patients in a terminal stage of their life deals with the idea of death inside families and turns it into a routine phenomenon. This topic raises many individual and family issues, which demonstrates the importance of it being discussed and (re)elaborated in order to have a better understanding of human finitude.

In the majority of cases, the caregiver is a relative close to the patient who assists him/her for an undetermined period of time. This continuous involvement generates a degree of distress that comes from dealing with the disease and the imminence of the death of the family member. Therefore, there is a need to know the perception of the caregiver in terms of the quality of life, work overload and human finitude, as well as the psychosocial implications associated with a role which is fundamental in today's society.

GUIDING QUESTION

Which factors impact on the quality of life and the physical and emotional stress of the caregiver of a home cared patient?

AIMS

To determine the perception of home caregivers with regard to the quality of life and work overload, their relationship to human finitude, and the psychosocial implications of assisting home cared patients.

METHOD

This is a descriptive and exploratory study, involving a cross sectional and qualitative appro-

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ach. The caregivers of patients who are in home care will participate in this study. The defining inclusion criteria are being a home caregiver of a patient actively enrolled in a Regional Center for Home Care (RCHC), being over 18 years of age, giving consent to participate in this research by signing the Free and Clear Consent Agreement. The exclusion criteria are being an assistant caregiver and being less than 18 years of age. A criterion of saturation with regard to the data being collected will be used to limit the number of participants in terms of the repetition of information without the addition of new elements to the research. To collect the data, a process which took place between March and September 2013, six validated instruments will be used. These are: 1. A questionnaire to collect sociodemographic data; 2. *World Health Organization Quality of Life Instrument Bref* (WHOQOL-bref); 3. *World Health Organization Quality of Life Instrument Old* (WHOQOL-old) – for caregivers above sixty years of age; 4. Caregiver Overload Scale (COS); 5. Profile of Reactions when Facing Death; 6. Semi-structured interviews with guidelines, based on the following areas: a. from initial diagnosis to home care treatment; b. the meaning of the illness; c. the meaning of death; d. feelings about suffering; e. changes in caregiver's routine.

The data will be analyzed using the software *Statistical Package for the Social Sciences*® (SPSS), version 13.0. In addition, content analysis technique will used with regard to the semi-structured interview data. Diagrams of dispersion will be designed to help to analyze the correlations between the results found through the use of the applied instruments.

REFERENCES

1. Brasil, Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Atenção Básica. Caderno de atenção domiciliar. Brasília, 2012. 2 v.
2. Born T. Cuidar Melhor e Evitar a Violência - Manual do Cuidador da Pessoa Idosa (org) – Brasília: Secretaria Especial dos Direitos Humanos - Subsecretaria de Promoção e Defesa dos Direitos Humanos, 2008;
3. Sousa A. França J. Nóbrega M. Fernandes M. Costa S. Palliative care: a conceptual analysis Online Braz J Nurs (Online) [internet]. 2010 August 30 [##plugins.citationFormats.vancouver.cited## 2013 Aug 5] 9(2):. ##plugins.citationFormats.vancouver.availableFrom##: http://www.objnursing.uff.br/index.php/nursing/article/view/2947. doi: http://dx.doi.org/10.5935/1676-4285.20102947

Authors and participation in the research

Diane Maria Scherer Kuhn Lago – participated in the research, elaboration, data collection and structure of the foreword.

Dirce Guilhem – participated in tutoring and structure of the foreword.

Project Data

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