The Caregiver Role in Palliative Care: A Systematic Review of the Literature

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Abstract

Patients nearing the end of their life are daily confronted with complex decisions. Is essential to ensure the continuity of care outside of the health institutions and, in this sense, a presence of a family member at home able to provide multilevel care has become an important goal/resource for patients and health care teams.

Aim: To analyse the literature about roles and tasks of family caregivers of patients in palliative care (PC).

Design: A systematic review of the literature published in English, Portuguese and Spanish between 2006 and 2014 was undertaken, in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Data sources: PubMed, PsycInfo, Scopus and SciELO were searched to find studies on the family caregiver’s role in palliative care.

Results: A total of 13 studies were included and described seven major caregiver roles: to be a caregiver, to be a welfare enhancer, to carry out many tasks, to act as a PC facilitator and be responsible for the continuity of care, to be an apprentice, to be a minimizer/manager of the suffering and to be a decider at the end-of-life.

Conclusions: Family caregivers are still the greatest support of patients in end-of-life especially when they wish to be cared for at home. Carers can be considered the core structure for the continuity of care of these patients. Setting out the various carer tasks and roles will contribute for the “family caregiver” agreement concept as well as, will recognize their value as a person who needs to be cared too.

Introduction

Caring for someone in a palliative stage is effortlessly understood as a moral duty and family members are the privileged group for this purpose. The palliative care (PC) philosophy argued that this function should be monitored and supported by specialized teams since they are trained and focused on pain relief, including the suffering of the family. However, and although unintentionally, only material benefits at home (e.g. Technical aids), is given to family carers to support them, which can increase their suffering due to their social isolation [1].

Family carers wellbeing mostly depends on the attitudes of the health care teams through their communication, active listening and knowledge. Genuine attitudes as family training and empowering are described in several studies with successful results [2-4]. Defined the “hands on care” as those who provide directly and/or indirectly care for the person with a terminal illness [5]. This study highlighted that this sort of experience allows caregivers to learn with their own experiences and helps to growth in their personal and spiritual matters. However, it can cause negative feelings as well, touching the significance of their own existence [6].

Usually, family caregivers are women, with a mean of 50 years old, spouses and children, which are negatively affected in their quality of life, watching the deterioration of their sick family member [7,8]. Nevertheless, studies in this area are mostly focused on cancer patient’s caregivers and little is known about the reality of non-cancer patient’s family carers.

A systematic review of the literature from 2000 to 2011 sought to meet this challenge by asking caregiver experiences with Amyotrophic Lateral Sclerosis (ALS) patients. A total of 59 articles were studied showing that it is imperative that the caregiver has information about the diagnosis and cognitive-behavioral consequences of this pathology, and that in some moment of the disease trajectory they will be requested to participate in important treatment decisions, such as to receive assisted ventilation. The same review alerted to the fact that most of the studies in this area were focused on the description of the profile of these family carers, instead of focusing on the development of interventions aiming to assist the caregivers to cope with their everyday emotions, instrumental and spiritual issues [9].

Considering that family caregivers ensure the continuity of patient care at home, PC teams should understand the role and tasks of their performance and must be prepared to identify and help them to work out their needs, as well as educate them in activities of care and self-care [10]. With this in mind, we propose to analyze the activities and roles undertaken by family caregivers of patients in PC literature.

Method

A systematic search of the literature was undertaken between January 2009 to December 2014 using the following combinations of terms (Palliative care [title] OR Hospice [Title]) OR End-of-
life [Title] AND Caregivers [Title]) OR family [Title] AND scroll [Title / Abstract]). Articles in English, Portuguese and Spanish were included. Electronic databases were searched in PubMed, PsycINFO, Scopus and SciELO using the EndNote X7 and Excel softwares. Only original articles published in scientific journals were included and the population was selected over 18 years of age. Pediatrics studies, books, doctoral and/or master’s degree theses, case studies, and literature reviews were excluded. For evaluating the quality of each article, the Hawker method was used [11].

All articles were selected, analyzed and classified by two independent reviewers according to their quality, and there was a third reviewer for situations of doubt or lack of consensus between the two main reviewers.

Search strategy

The selection of the articles was made in three moments taking into account the criteria delineated above and based on the research question: What tasks / activities and functions are met by family caregivers of patients in PC?

First, the primary reviewer examined the titles identified in the database, deleted the duplicate ones, and selected those titles considered relevant for the study. Secondly, two independent reviewers analyzed the abstracts flagged by title, and they excluded those that did not seem relevant to answer the research question; the third step included the full reading articles and selection.

Concepts

This study took into account the following concepts:

Family caregiver/Caregiver’s- relatives, friends, neighbors and all those who attend voluntarily the patient daily care [12].

Tasks/Activities - any work, occupation, obligation, utility and other actions that could describe a caregiver experiment in the context of PC.

Role - the set of tasks or activities that defines a sociocultural representation [13].

Type of study

The classification and quality assessment of the studies was based on an instrument developed by, used for quantitative and qualitative research [11]. This tool allows to classify each article on a scale of 1 to 4 points (1 "very poor", 2 "poor", 3 "satisfactory", 4 "good"), evaluating nine distinct parameters: title and abstract, introduction and intent, method and data, sample, data analysis, ethics and bias, results, implications, degeneracy and utility. Adding up the scores resulting from each parameter will result from a value amid 9 to 36 (9 "Very poor, 36 "Good").

Results

A total number of 666 papers were identified of which 596 were excluded because of the title and duplicates. Secondly, 70 abstracts were read and, of those, 38 were excluded for not answering the research question. Thus resulting in 32 articles of which 25 were excluded after reading the full article. Six articles were added to this selection due to their relevance (Figure 1).

Hence, this systematic review includes thirteen original articles published from January 2009 to December 2013. Two studies have been conducted in Sweden, one in the United kingdom, one in Thailand, two in Norway, one in Brazil, two in Australia, two in the United States, one in Taiwan and Canada. Altogether, 13 studies were included in this systematic review adopted qualitative research methods. The majority of the articles was rated as being "good" (n = 11); the other two articles were considered as being "sufficient" The total scores can be seen on Table 1.

In all 13 studies include informal caregivers (family or close friends) of patients with severe disease (cancer or not) in palliative condition as participants, followed by teams of PC or Intensive Care units (ICU's). Six studies intended to examine the influence of gender, skills, experiences and needs of carers in their home environment and two studies tried to do it in a hospital setting [6,14-18]. One study reported caregivers experiences with ventilated patients at home, and other showed the evidence of caring for patients with Amyotrophic Lateral Sclerosis (ALS) [12,19].

(Table 1 – Included studies: general characteristics (n=13) – here)

(Table 2- Tasks, activities or family roles description (n=13) – here)

Four studies did not specify the setting of care where the patient was during the data collection [9,13,16,17,20-22], and four did not make reference to the fact that the patient was followed or not by a PC team.

Data Analysis

The role that each caregiver has in the society and in the family system, integrates different tasks and activities. The analysis of the selected articles originated seven main roles (Table 3).

(Table 3 – Palliative Caregivers Role – here)

The caregiver can fill the role of being a ‘caregiver’. They accept the caring as a natural action, presumably imposed by the society and fulfilling a moral obligation. The caregiver also assumes the role of being a ‘Well-being enhancer’ by undertaking the task of keeping the hope of the patient, maintaining the marital relationship, and helping to provide balanced activities to help the family to rest and cope with the situation they are experiencing; providing religious rituals and satisfying the wishes of the patient are also part of this role.
<table>
<thead>
<tr>
<th>1st Author/ year</th>
<th>Country</th>
<th>Qualitative Data</th>
<th>Patients</th>
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</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Munk, B. (2008)</td>
<td>Sweden</td>
<td>Exploratory, descriptive; semi-structured interview; Critical incident</td>
<td>Followed by the domiciliary PC team, died in unspecified hospital units</td>
<td>People close to the patient who provided home care, mourners up to 18 months (n = 9)</td>
</tr>
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<td>2</td>
<td>Brazil, K. (2009)</td>
<td>Canada</td>
<td>Descriptive; longitudinal, interview; Barthel Index; Robinson Caregiver Strain Scale</td>
<td>Terminal illness, with no reference to the place of care</td>
<td>Spouses, &gt; 50 years, use of community services, social centers/health (n = 283)</td>
</tr>
<tr>
<td>3</td>
<td>Lau, D.T. (2009)</td>
<td>Chicago</td>
<td>Interview coding</td>
<td>≥ 60 years with chronic pathology and receiving support of Hospices Care Programs</td>
<td>People ≥ 18 years, responsible for managing the patient’s medication at home (n = 23)</td>
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<td>4</td>
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<td>Open and semi-structured interview</td>
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<td>Adults deceased at a university hospital</td>
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<td>8</td>
<td>Harding, R. (2012)</td>
<td>UK</td>
<td>Descriptive, cross-sectional Semi-structured interview</td>
<td>Cancer patients followed by PC Community Support Team</td>
<td>Informal carers, ≥ 18 years, who performed unpaid physical and emotional home care and were identified by the patient as “primary caregiver” (n = 20)</td>
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<td>Interview and narrative analysis Discussion of results in research group</td>
<td>Accompanied by units and teams who provide PC at home</td>
<td>Family caregivers (n = 14)</td>
</tr>
<tr>
<td>10</td>
<td>Quinn, J.R. (2012)</td>
<td>USA</td>
<td>Prospective study; Ethnographic method Participant observation and semi-structured interviews</td>
<td>Patients at end of life, admitted to ICU</td>
<td>Families, nurses, doctors, other professionals and patients (n = 138)</td>
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<td>Symbolic interactionism Delphi</td>
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<td>Australia</td>
<td>Exploratory Questionnaire and interview</td>
<td>Amyotrophic Lateral Sclerosis patients who were offered PC</td>
<td>Bereaved spouses (between 1 and 4 years) (n = 13)</td>
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*Quality Evaluating (Q.E.) of each article, Hawker et al. (2002). * 

Table 1: Included studies: general characteristics (n=13).
To attend to the patient’s hygiene care; Naturally assume the caregiving role socially imposed (caregiving role).

To be available day and night (24 hours/day); To keep the patient’s hope up; To be physically and mentally available 24 hours a day; To not lose control; To satisfy the patient’s desires; To be responsible for the patient; To be a pillar of the patient’s intensive care; To transport the patient to appointments; Troubleshoot nutrition and evacuation problems of the patient.

Caregiving as a dynamic process; Emotional and cognitive care; Learn to deal with fan, monitor and other technical aids; responsibility to care; To control; have clinical information; care of the patient-caregiver; assume the role of doctor, nurse, therapist; forced to care;

To provide care due to moral obligation; Learn about caregiving procedures; Dealing with grief; To help (to provide a helping relationship); To assist the patient in the dying process.

Caregiving day to day; Do several practical activities; Be attentive to emotional aspects; Manage medication, prepare meals, bathe, shave; support during night.

Caregiving as a moral obligation

Tasks / Activities | Role
--- | ---
Naturally assume the caregiving role socially imposed (caregiving role) | Caregiver
Caregiving as a moral obligation | Well-being Enhancer
To be available 24 hours / day | Minimizer / Manager of suffering
To keep the patient’s hope up | "Handyman"
To satisfy the patient’s wishes | PC facilitator and responsible for the continuity of care
To help (providing a helping relationship) | Learner
To maintain the marital relationship | "Experts" on health care.
To support the remaining family | "Experts" on health care.
To provide religious rituals | "Experts" on health care.
To participate in patient comfort | "Experts" on health care.
To transport the patient to appointments | "Experts" on health care.
Troubleshoot nutrition and evacuation problems of the patient | "Experts" on health care.
To attend to the patient’s hygiene care | "Experts" on health care.
To be with the patient at the hospital | "Experts" on health care.
To ensure household tasks | "Experts" on health care.
To continue to work while providing care | "Experts" on health care.
Massage the patient | "Experts" on health care.
To provide and manage medication | "Experts" on health care.
To cope with the patient’s suffering | "Experts" on health care.
To play and share emotions | "Experts" on health care.
To talk with the patient | "Experts" on health care.
To pray | "Experts" on health care.
To assist in the dying process | "Experts" on health care.
To have empathy and be understanding | "Experts" on health care.
Presence | "Experts" on health care.
To give and receive compassionate care | "Experts" on health care.
Living with uncertainty | "Experts" on health care.
To face illness alongside the patient | "Experts" on health care.
To be a pillar of intensive support for the patient | "Experts" on health care.
To not lose control | "Experts" on health care.
Learn ways to provide care | "Experts" on health care.
To assume responsibility for the patient | "Experts" on health care.
To participate in decision-making processes, including end-of-life decisions | "Experts" on health care.
To be informed | "Experts" on health care.

Table 3: Palliative Caregivers Role.
To the extent that the family caregiver performs multiple activities over 24 hours / 7 days a week, consecutively or not, they undertake the role of being a "Diversity of tasks' fulfiller" (e.g. transferring the patient to medical appointments, doing hygiene care, ensuring housekeeping, massage, managing and administering medication).

Being 24 hours a day with the patient require that caregivers are be physically and mentally available. During this time the caregiver is enforced to deal with grief and often takes the role of a "Minimizer/ Manager of suffering", sharing emotions, showing empathy and understanding, praying, talking to the patient, helping the patient to deal with the end of life experience and dying peacefully.

Another role of the caregiver is to be a "PC facilitator and responsible for the continuity of care". Taking the patient disease along and being present, applying and receiving compassionate care, reflects that the career is undoubtedly the pillar of patient security. This is why the family carers is often seen as part of the health care team.

In several studies, the role of the family caregiver was associated with decision-making, assuming the role of "Decider at the end-of-life". This role incites a sense of obligation and at the same time, a feeling of anguish, particularly when these decisions refer to medical decisions.

Discussion

The unexpected presence of the disease within a family is responsible for the outbreak of new occupations and concerns that profoundly affect the family. Furthermore, many governments, health schemes, and social institutions just offer a little support to family caregivers increasing the suffering and burden caused by such situations [4]. Therefore, health professionals, particularly PC teams, have to be aware of the many tasks and activities assumed by the family and informal caregivers at end of life in order to minimize the physical and emotional burden they often face.

Socially assigned and intrinsically assumed, the function of the family "caregiver" is mostly understood as a voluntary and not tax job [23]. However, sometimes family carers take care of their ill relatives due to moral obligation and their beliefs of being ready and capable of doing their best [6,10]. Reported that 90% of the care of dependent patients are provided by family carers and this means being available day and night (24 hours/day), supporting the patient, meeting and reducing their suffering [16,23].

The primary caregiver, who is normally the nearest person, usually provides physical, psychological, social and spiritual care, aiming to promote the well-being of the patient, relatives and friends, allowing the patient to be cared for at home, and also contributing to cost reduction in health [3,15]. In the articles included in this systematic review, some caregivers who were not supported by health care teams often lost control of the situation, which was perceived as a negative experience [23]. Other studies reported gender differences caregiving role. "Caregiving role", Female carers tend to have more burnout levels and receiving less assistance due to moral obligation and their beliefs of being ready and capable of doing their best [6,10].

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Although, it is known that cultural factors can determine the concepts of physical, spiritual and psychological maintenance, It is universally admitted that patients have three basic needs: security, integrity and sense of life; sense of belonging [25]. Most part of these needs can be suppressed by family carers, especially because of the intimacy in the relationship shared with the patient. Everything will depend along the feeling of love and the quality of the relationship established between the patient, the caregiver, and the PC team.

Conclusion

A concrete knowledge about the actions done by caregivers can facilitate good clinical and psychosocial practices, in particular in the context of PC where the family simultaneously provides and receives health care.

For the well-being of the patients, the caregivers perform distinct activities added to those they have in their own personal routine (Table 3), which is essential for the continuity of care of the patient at the end of life, both at the hospital as at home. This systematic review has shown that although universally recognized, the role of the family caregiver is still poorly supported by society, health teams and family systems.

Family members who are close to the patient may play the role of caregiver, well-being enhancer, diversity of tasks’ fulfiller, minimizer and managing suffering (patient and himself), PC facilitator and responsible for the continuity of care, apprentice and participant of health teams. They also play the role of controller because they often have to take decisions, although the sick person concern and not to
Increased global visibility of articles through worldwide distribution and indexing
700 Open Access Journals
Better discount for your subsequent articles
Indexing at PubMed (partial), Scopus, EBSCO, Index Copernicus and Google Scholar etc
Rapid review process
Special issues on the current trends of scientific research
Authors, Reviewers and Editors rewarded with online Scientific Credits
50,000 editorial team
Showcasing recent research output in a timely and updated manner
Sharing Option: Social Networking Enabled
Quality and quick editorial, review and publication processing
Indexing at PubMed (partial), Scopus, EBSCO, Index Copernicus and Google Scholar etc
Sharing Option: Social Networking Enabled
Authors, Reviewers and Editors rewarded with online Scientific Credits
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References