



Review

The experience of family caregivers caring for a terminal patient at home: A research review

J. Martín Martín^{a,*}, M. Olano-Lizarraga^a, M. Saracíbar-Razquin^{a,b}^a University of Navarra, Faculty of Nursing, Pamplona, Spain^b Navarra's Health Research Institute (IdiSNA), Pamplona, Spain

ARTICLE INFO

Article history:

Received 19 February 2016

Received in revised form 13 September 2016

Accepted 13 September 2016

Keywords:

End of life care
 Family caregiver
 Home care
 Experience
 Nursing
 Terminally ill

ABSTRACT

Introduction: One of the key aspects of the care of terminal patients is care delivered in their own home. Increasingly, the process of dying is moving from hospitals to homes. Although this process is directly related to the support of the social health environment, the involvement of family caregivers is essential. Given the impact that caring for a terminally ill family member has on people's lives, it is necessary to comprehend their personal experience in a holistic way.

Objective: To reveal the experience of family caregivers who are caring for a terminal patient in their home.

Design: A qualitative systematic review of articles published from 2000 to 2015 was conducted between March and September of 2015. The following databases were consulted: CINAHL, PubMed, PsycINFO, Cochrane Library, SciELO and Dialnet. After applying the selection criteria, 12 relevant studies were identified. Subsequently, two of the reviewers jointly performed a qualitative content analysis of them. *Results:* The analysis permitted the caregivers' experiences to be grouped into five themes: 1) Learning the diagnosis: uncertainty about the future and the prospects of death; 2) Feeling the physical and emotional burden of care; 3) Experiencing a limited life; 4) Redefining the relationship with the person being cared for; and 5) Valuing the importance of the support of the environment.

Conclusions: This review shows that caring for a family member with advanced illness in the home has a great impact on the personal realm of the caregiver and in the relationship he or she maintains with the ill family member. Being involved in the process of dying translates into a prodigious physical and psychological effort, together with a substantial limitation on the normal development of their own life. Additionally, the caregiver must face and establish a new relationship with the family member, in accordance with the new *ethos*, without the help of a formal structure providing the necessary support. These results may help to focus attention on family caregiver needs and to develop the knowledge necessary to meet the current demands of end-of-life health care in the home.

© 2016 Elsevier Ltd. All rights reserved.

What is already known about this topic?

- An increase has occurred in people's desire to die at home, together with an increase in doing so. Policies and strategies for home assistance at the end of life are being developed; however, they remain insufficient in all countries equally.
- Family caregivers constitute a fundamental pillar in the informal care of terminal patients in the home.
- The needs and challenges experienced by family caregivers at the end of life may be greater than those of the terminally ill patients themselves.

What this paper adds

- The results obtained from the qualitative systematic review offer a holistic view of the experience of family caregivers who are caring for a terminal patient in the home.
- Nursing professionals should recognise the personal significance of the experience of caring for a terminal family member in the home and respond to the actual expectations and needs of these caregivers.
- The need to promote and conduct research that elucidates the knowledge necessary for nurses to understand and adequately care for family caregivers and to promote social health policies that improve caregiver support.

* Corresponding author at: University of Navarra, Faculty of Nursing, Pamplona, Spain, C/Irunlarrea, 1, Postal Code: 31008.

E-mail addresses: jmartin.19@alumni.unav.es (J. M. Martín), molizarraga@unav.es (M. Olano-Lizarraga), mis@unav.es (M. Saracíbar-Razquin).

1. Introduction

Currently, one of the key aspects in the area of family end of life caregiving is home care. Although the number of deaths in hospital institutions continues to be high, home deaths have increased (Higginson et al., 2013; Morris et al., 2015). For example, in England between 2004 and 2011, the proportion of home deaths increased from 18% to 22%, whilst hospital deaths decreased from 58% to 51% (Department of Health, 2012). Notwithstanding, a great discrepancy remains between the proportion of people who die in the home (22%) and those who would prefer to do so (63%) (Gomes et al., 2011). In this sense, it is important to note that, although 90% of terminally ill patients are cared for at home in their last year of life (Van den Block, 2012; Wheatley and Baker, 2007), patients continue, for various reasons, to be admitted into health institutions in the last days or hours of life to die. Because of these circumstances, countries such as the United Kingdom, the United States, Australia and Canada are pursuing socio-political strategies to improve end of life home care (Munday et al., 2007; Costantini, 2008; Fukui et al., 2011; Gomes et al., 2013).

Although end of life care at home is directly related to the support of the social and health environment (Drieskens et al., 2008; Fukui et al., 2011), the involvement of family caregivers is essential (Gomes and Higginson, 2006; Alonso-Babarro et al., 2011). The probability of a patient dying at home depends greatly on their efforts and their capacity to take charge of the caregiving (Gomes and Higginson, 2006). Even when patients have home health care services available, their option to die at home is drastically reduced if their family members cannot provide the necessary caregiving (Grande and Ewing, 2008). For this reason, family caregivers are analogous to the backbone of end of life care (Stajduhar et al., 2010), providing approximately 80% of home patient care (Stajduhar, 2013).

Recognising caregivers' labour and the challenges they face (Andershed, 2006) has led to family caregiving being established as an international research priority for end of life care (Hagen et al., 2006; Stajduhar et al., 2010). Hence, numerous studies have emerged recently centred on the experience of family caregivers of terminally ill patients (Funk et al., 2010; Morris et al., 2015). Nevertheless, the relevance and depth of this phenomenon necessitates a more substantive understanding (Peacock et al., 2014; Morris et al., 2015). Additionally in this regard, it warrants noting that the studies conducted to date have tended to employ quantitative methods, centred on specific and predetermined variables (Kukeya, 2006), thus limiting the understanding of this experience (Peacock, 2011). Together with this observation, it is noteworthy that the qualitative studies to date have focused their questions on specific variables, for example, decision making and pain or grief management. These delimited approaches have permitted a better knowledge of these specific phenomena, but

they have not made it possible to holistically access the experience of these families with a global and unified vision (Funk et al., 2010).

Given the impact that caring for a terminally ill family member has on people's lives, it is particularly important to comprehend their personal experience in a holistic way, as well as its significance. This orientation toward understanding the concrete experience of the protagonists of this phenomenon has been maintained in the vision of the nursing profession, whose practice is based on the experiences of people's health and illness (Benner, 1984). In accordance with the current paradigm of nursing, to know and understand this experience and the significance it has for caregivers in this situation may help nursing professionals to better focus their care and thus to improve caregiver well-being and quality of life (Saracibar Razquin, 2009). Similarly, this knowledge may be relevant when planning, managing, and executing health policies related to family caregiving at end of life. Therefore, this study aims to discern the holistic experience of family caregivers who are caring for a terminal patient in the home, based on a qualitative systematic review which was conducted between March and September of 2015.

2. Methodology

With the goal of revealing the experience of family caregivers who care for a terminal patient in the home, we first conducted a qualitative literature review using a systematic methodology followed by a qualitative content analysis of the selected studies. Qualitative content analysis is commonly used in nursing studies (Elo et al., 2014) to examine the data and interpret their meaning (Schreier, 2012). In addition, it offers researchers important benefits, such as sensitivity toward the content of the data (Krippendorff, 1980) and flexibility in terms of the study design (Harwood and Garry, 2003). Its final objective is to obtain a condensed and broad description of the phenomenon of interest (Elo and Kyngäs, 2008).

2.1. Search strategy

The literature review was performed in the CINAHL, PubMed, PsycINFO, Cochrane Library, SciELO and Dialnet databases. The key words used were "experience", "family caregivers", and "end of life", with their respective synonyms, identified from MeSH terms, from the thesaurus and from the literature. Boolean operators ("AND" and "OR") and truncating words were used to include possible variations used in the literature. In addition, the searches were limited to the last 15 years (01/01/2000–31/09/2015) and were restricted by language (English or Spanish) and population (adults). To minimise the likelihood of excluding important studies, a certain degree of experimentation was required to develop an appropriate search strategy. Table 1 shows the search

Table 1
Final Search Strategy in CINAHL .

No.	Keywords (Search Modes: Boolean/Phrase)
1	"liv* with" OR "liv* experienc*" OR "experienc*" OR "life" OR "perspectiv**"
2	"famil**" OR "family car**" OR "family caregiv**" OR "relativ**" OR "next of kin**"
3	"end of life" OR "palliative" OR "terminal" OR "dying" OR "last days"
4	"Care**"
5	1 AND 2
6	3 AND 4
7	5 AND 6
8	5 AND 6 (Limits: English, Spanish, All Adult, 01/01/2000–31/09/2015)

Download English Version:

<https://daneshyari.com/en/article/5121035>

Download Persian Version:

<https://daneshyari.com/article/5121035>

[Daneshyari.com](https://daneshyari.com)