



Original Article

Analysis of the transition process among family caregivers in a hospital in the region of Catalonia in Spain



Gerard Mora-López ^{a,*}, Carme Ferré-Grau, PhD, RN ^{b,1}, Pilar Montesó-Curto, PhD, RN ^{c,2}

^a Joan XXIII University Hospital of Tarragona, Department of Nursing, Rovira i Virgili University, 13–15, Remolins Avenue, Tortosa, 43500, Tarragona, Spain

^b Department of Nursing, University Rovira i Virgili (Tarragona), 34 Catalunya Avenue, Tarragona, 43002, Tarragona, Spain

^c Department of Nursing, University Rovira i Virgili (Tarragona), 13–15, Remolins Avenue, Tortosa 43500, Tarragona, Spain

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ABSTRACT

Purpose: The aim of this study is to explore and understand the experience of the adaptation process among family caregivers in hospitals, who have an active presence in hospital and are essential in ensuring proper patient care.

Methods: A qualitative phenomenological approach was used to gain a deeper understanding of caregivers' lived experiences. Data were collected using in-depth interviews to explore six caregivers' experiences of hospitalization.

Results: The caregivers' accounts highlight the different determining factors in the transition process of a chronically ill patient's family caregiver during the patient's time in hospital. The most important themes emerging from the analysis were the importance of cultural beliefs and attitudes, meaning of the situation, caregiver's training and knowledge, socio-economic status and the hospital as a community. These categories can be analyzed using transitions theory.

Conclusions: The most important conclusion is that the hospital in this study was not designed to accommodate caregivers, and the mechanisms used to meet caregivers' needs endanger their privacy, health, and coexistence in the hospital's rooms. Transitions theory provides a holistic understanding of the experience of the family caregiver.

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1. Introduction

The study was carried out in Catalonia (Spain), where the increase in life expectancy at birth and the decline of the birth rate have led to an ageing population and increased prevalence of chronic diseases. In this region, most care required by dependent individuals is the responsibility of the main caregiver, who is usually a relative of the person receiving care, and whose profile is characterized by a lack of any specific training for the tasks of caring, no financial remuneration for this work, a high level of commitment towards the work, and their emotional involvement and provision of care 24 hours a day, 365 days a year.

Care for the person who has a chronic disease is administered at home. However, when the patient's situation changes, families often ask their referral hospital to admit the patient. The patient is accompanied by a main caregiver/family member, who spends 24 hours a day in the hospital (Ferré-Grau, Rodero Sanchez, Vives Relats, & Cid Buera, 2008).

Hospital admission is the gateway into a world of conventions and symbols, colors, uniforms, and linguistic codes that are often not understood by patients or their caregivers. Both feel disoriented, as well as experiencing a situation of dependence and inferiority. Hospitals in Spain have never been designed to accommodate family caregivers. Despite the need for them when accompanying patients, they are a secondary concern and suffer from low levels of visibility.

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2. Literature review

In the literature review, we found many references to family caregivers in the home environment, (Crespo López, 2007; Zarit & Bach-Peterson, 1980) but very few referring to hospitals, although interestingly, research in this field has increased considerably in recent years (Bastani, Golaghaie, Farahani, & Rafeie, 2013; Lowson et al., 2013; Robinson, Gott, & Ingleton, 2014). One of the studies carried out in Spain (Celma Vicente, 2001) highlights the lack of care provided for caregivers in hospitals. This study described the various profiles of hospital companions and suggested a model for continuous training for professionals aimed at defining a conceptual framework and a working methodology

* Corresponding author. Tel.: +34 646433434.

E-mail addresses: gerard.mora@urv.cat (G. Mora-López), carme.ferre@urv.cat (C. Ferré-Grau), maripilar.monteso@urv.cat (P. Montesó-Curto).

¹ Tel.: +34 977 29 94 41.

² Tel.: +34 977 464 030.

for nursing to facilitate comprehensive care for patients and their families.

To ascertain the quality of life of companions of patients hospitalized on a medium- and long-term basis, Flores et al. (2002) conducted a qualitative study using semi-structured interviews of fifty-six family caregivers. The study showed that the companions were not comfortable in the hospital due to limited space, lack of privacy, and poor quality of sleep. In psychosocial terms, most caregivers presented anxiety, fatigue, and strong feelings of loneliness or insecurity (Bektas, Cebeci, Karazeybek, Sucu, & Gursoy, 2012; Chiu et al., 2014; Nakagami et al., 1999).

According to Flores et al. (2002), the most important social variable was economic impact, since some of the family caregivers had had to give up their jobs due to the patient's hospitalization. The researchers noted a lack of protocols recognizing the role of the caregiver. Noteworthy recent research includes a study by Quero Ruffian (2003, 2007). The main conclusions of this study were that family caregivers have an active presence in hospital and are essential to ensure proper patient care.

A transition is the passage between two stable periods of time (Meleis, 2010). During this period, the individual moves from one phase, situation or life condition to another. Therefore, transitions are processes that occur over time and involve reorganization, with a new sense of purpose. Conditions are the circumstances that influence how an individual moves towards a transition. These may facilitate or hinder progress in achieving a healthy transition. These conditions include personal, community, and social factors. Personal factors encompass cultural significance, beliefs and attitudes, socio-economic status, education and knowledge, while community conditions refer to community resources, and social factors to social relationships.

Afaf Ibrahim Meleis' transitions theory (Meleis, 2010; Zagonel Sanson, 1999) was the framework of reference used in the study to identify factors that can facilitate or hinder the transition process of a family caregiver of a chronically ill patient in the hospital environment.

3. Objectives

This article aims to analyze the feelings, activities, and perceptions of family caregivers of dependents in a hospital and to describe the factors influencing the adaptation process among family caregivers in hospitals, according to Meleis' transitions theory (Meleis, 2010).

Understanding the experience of caregivers in the hospital environment is an important factor in improving aspects relating to the comprehensive care of dependent patients and their families.

4. Methods

4.1. Research design

In accordance with the objectives of the study, a qualitative phenomenological approach was used, as this is considered highly appropriate for examining the qualities of human experience (Wimpenny, 2000).

Giorgi (2006) argues that the participant is the expert on the phenomenon under investigation; the researcher may know about theories and the literature, but does not know the relevant dimensions of the specific experience being reported by a participant. Indeed, phenomenological research enables the researcher to enter the participant's life world to gain a deeper understanding of his or her experience (Balls, 2009).

Symbolic interaction is a hermeneutic process—dialectic since the time of interpretation and comparison. By contrast, phenomenology describes the experience as it occurs, devoid of interpretations. In this study, phenomenology is used to capture and understand symbols and meanings of family caregivers in a hospital in the cultural environment of Catalonia, Spain.

4.2. Participants

This study included a sample of six family caregivers. The profiles of the caregivers were obtained through interviews with professionals, supervisors, and nurses in the inpatient hospital units at the Hospital de Tortosa Verge de la Cinta (Tortosa), and from a literature search. Participants were recruited between November 2011 and May 2012 in the hospital's internal medicine, surgery, and urology units. The criteria for inclusion were: family caregivers over 18 years old of dependents, with at least 1 year's evolution of dependence. Based on these criteria, five female participants and one male were selected, who had the following characteristics:

- A 78-year-old woman, retired, who has cared for her sister with a history of chronic obstructive pulmonary disease (COPD) for the last 10 years, admitted for pneumonia and who had been hospitalized for 3 days. (C1)
- A 48-year-old woman on leave of absence from work to care for her mother suffering from Alzheimer's disease and leukemia, admitted 20 days ago due to general malaise. (C2)
- An 83-year-old man, retired, who cares for his wife with a history of osteoarthritis, admitted to hospital 25 days ago with a fracture of the femur. (C3)
- A 77-year-old woman, retired, who cares for her husband who suffers from COPD, who was admitted to hospital 3½ months ago for septic shock and undergoing a process of rehabilitation. (C4)
- A 63-year-old woman, housewife, accompanying her husband with a history of Parkinson's disease and heart failure, admitted to hospital 19 days ago due to hematuria. (C5)
- A 73-year-old woman, retired, who cares for her husband with a history of Alzheimer's disease who was admitted to hospital 8 days ago for a surgical procedure. (C6)

We stopped the interview process following the principle of saturation of information. We are aware that carer types are very homogeneous and that future studies should involve carers with different features.

5. Data collection

We used an in-depth semi-structured interview with each participant lasting approximately 1 hour. Table 1 contains sample questions used in the semi-structured interview. These interviews were audio recorded and transcribed in full by the authors of this article. Data analysis was undertaken by means of in-depth reading of the interviews. The data analysis was carried out manually, line by line, sentence by sentence, using Glaser and Strauss' constant comparative method as proposed by Medina Moya (2005).

To provide reliable data and triangulate the information, results have been reviewed by three expert investigators in qualitative methodology and nursing models.

Table 1
Sample questions.

Illness and hospital admission
Can you explain to me the illness of your family member?
How did you feel when you came to the hospital?
Life in hospital
What tasks do you do to take care of your family member?
How do you feel about the staff?
For those who prefer to be served?
Do you know who the nurse is and who is the nurse assistant?
Where do you eat in the hospital?
Beliefs
Do you believe in God? Do you think that God helps you?

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