

# The transition of palliative care from the hospital to the home: a narrative review of experiences of patients and family caretakers

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## The transition of palliative care from the hospital to the home: a narrative review of experiences of patients and family caretakers

**Objective.** This work sought to identify, analyze, and synthesize the qualitative studies published on the experiences of patients and family caretakers during the transition of palliative care from the hospital to the home. **Methodology.** A narrative review was conducted on the PubMed, Cochrane Central, ScienceDirect, Ovid Nursing, CINALH, Scielo, and Bireme databases, from 2000 to 2014. **Results.** After the analysis and comparison of the data, the results were grouped into six themes: (1) the dyad and its knowledge regarding the diagnosis and prognosis; (2) emotions experienced by the family caretaker and the patient during discharge; (3) effective communication among those involved with the care; (4) education for the care of the person at home; (5) continuous support to the dyad at home, and (6) care overload: social support for the family caretaker. **Conclusion.** Patients and relatives in palliative care experience a broad range of needs during the transition process from the hospital to the home, which are often not covered by healthcare professionals. This review evidences the need to research further on the experiences of these families, especially during the stage prior to the transfer to the domicile.

**Key words:** caregivers; palliative care; review; hospital discharge; home care services.

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## La transición de cuidados paliativos del hospital al hogar: una revisión narrativa de las experiencias de pacientes y cuidadores familiares

**Objetivo.** Identificar, analizar y sintetizar los estudios cualitativos publicados sobre las experiencias de pacientes y cuidadores familiares en la transición de cuidados paliativos del hospital al hogar. **Metodología.** Se realizó una revisión narrativa en las bases de datos PubMed, Cochrane Central, ScienceDirect, Ovid Nursing, CINALH, SciELO y Bireme, desde 2000 a 2014. **Resultados.** Tras el análisis y comparación de los datos, los resultados se agruparon

en seis temas: (1) la diada y su conocimiento ante el diagnóstico y pronóstico; (2) emociones experimentadas por el cuidador familiar y el paciente durante el alta; (3) comunicación efectiva entre los actores del cuidado; (4) educación para el cuidado de la persona en el hogar; (5) apoyo continuo a la diada en el hogar, y (6) sobrecarga del cuidado: soporte social para el cuidador familiar. **Conclusión.** Los pacientes y familiares en cuidados paliativos experimentan un amplio rango de necesidades durante el proceso de transición entre el hospital y el hogar, que en ocasiones no están cubiertas por parte de los profesionales de la salud. Esta revisión evidencia la necesidad de seguir investigando sobre las experiencias de estas familias, especialmente en la etapa previa al traslado al domicilio.

**Palabras clave:** cuidadores; cuidados paliativos; revisión; alta del paciente; servicios de atención de salud a domicilio.

### **A transição de cuidados paliativos do hospital ao lar: uma revisão narrativa das experiências de pacientes e cuidadores familiares**

**Objetivo.** Identificar, analisar e sintetizar os estudos qualitativos publicados sobre as experiências de pacientes e cuidadores familiares na transição de cuidados paliativos do hospital ao lar. **Metodologia.** Realizou-se uma revisão narrativa nas bases de dados PubMed, Cochrane Central, ScienceDirect, Ovid Nursing, CINALH, Scielo e Bireme, desde 2000 a 2014. **Resultados.** Depois da análise e comparação dos dados, os resultados se agruparam em seis temas: (1) a dupla e seu conhecimento ante o diagnóstico e prognóstico; (2) emoções experimentadas pelo cuidador familiar e o paciente durante o alta; (3) comunicação efetiva entre os atores do cuidado; (4) educação para o cuidado da pessoa no lar; (5) apoio contínuo à dupla no lar, e (6) sobrecarga do cuidado: suporte social para o cuidador familiar. **Conclusão.** Os pacientes e familiares em cuidados paliativos experimentam uma ampla gama de necessidades durante o processo de transição entre o hospital e o lar, que em ocasiões não estão cobertas por parte dos profissionais da saúde. Esta revisão evidencia a necessidade de seguir pesquisando sobre as experiências destas famílias, especialmente na etapa prévia ao traslado ao domicílio.

**Palavras chave:** cuidadores; cuidados paliativos; revisão; alta do paciente; serviços de assistência domiciliar.

## Introduction

According to the World Health Organization, at least 12 types of diseases exist in adults who require palliative care (PC), which is equivalent to a total of 19.2-million people who currently need this type of attention.<sup>1</sup> Palliative care is carried out by health professionals in centers with primary or specialized care, hospices, residences, and most are being treated at home.<sup>1</sup> In this sense, PC at home gains much importance when considered by patients and their family caretakers as the most desired type of attention during the final stage of life.<sup>2-5</sup> Additionally, studies have evidenced that home PC improves the quality of life of patients, increases satisfaction with care,

and generates positive economic impact for the healthcare system.<sup>6,7</sup>

In some countries, like those in northern Europe, the United Kingdom, the United States, or Australia highly developed PC services exist offering early accompaniment to patients and their families during the end of life and through different contexts (hospital-community). Rather, in other countries development of PC has been slower. Thus, for example, Latin America reports proportions of 1.63 PC units per every million inhabitants,<sup>8</sup> while European standards estimate that the proportion should be of five units per

every million inhabitants.<sup>9</sup> These proportions hinder satisfactorily covering the demands of patients and family caretakers.<sup>8</sup>

In the need to meet the demands of the patient-family caretaker dyad during the final stage of life,<sup>10</sup> it is important to consider the following. On the one hand, assuming home care supposes having basic knowledge and skills that in many cases patients and family caretakers ignore, leading them to endure difficulties for care. On the other hand, evidence has shown that the overload of family caretakers is related to the patient's daily care, with their preparation to assume said care and with support received from the different support networks.<sup>11</sup> All this may be because patients in PC present diverse symptoms for which they must receive multiple medication; besides, they show a high degree of functional deterioration and dependence. Even, emotionally, patients and caregivers must face the reality of death and thereafter, in the case of the families, grief. These considerations are translated into a situation that alters the quality of life of the family caretaker, as well as that of the person cared for.<sup>12</sup>

Upon this reality, it is necessary to better meet the challenges, needs, and difficulties confronted by patients in palliative care and their family caregivers, especially during the transition between the hospital and the home, to design effective interventions to respond to the specific needs of this population. The transition concept was studied for the first time in the Nursing discipline by Afaf Meleis,<sup>13</sup> who proposed that the transitions of human beings are complex, multidimensional, and have multiplicity patterns. From this perspective, nursing professionals play an important role for an adequate transition of the person and the family from the hospital to the home. Addressing this study topic from this framework may contribute to understanding the transition process between the hospital and the home, and the preparation patients and caregivers need for a positive transition. Hence, the aim of this article was to identify, analyze, and synthesize the qualitative studies published on the experiences of patients and family caretakers

during the transition of palliative care from the hospital to the home. In this study the transition from the hospital refers to the last stage of admission, which includes the hospital discharge; in addition, in this study the terms home and domicile are identified as synonyms.

## Methodology

A narrative review was conducted of qualitative studies<sup>14</sup> to respond to the aim of this work. PubMed, Cochrane Central, ScienceDirect, Ovid Nursing, CINALH, Scielo, and Bireme databases were revised, limiting the search between January 2000 and February 2014 in English and Spanish. The search was limited to this interval of years to provide the most recent evidence; besides, it is worth mentioning that it was after 2000 when an exponential growth of publications appeared on palliative care, being an area of recent development within the setting of Health Sciences (the term MeSH "Palliative Care" was introduced in the late 1990s). Also, through the snow-ball technique, lists of bibliographic references were reviewed manually of articles selected to be included in the study and the same general selection criteria were applied.

Table 1 describes the key words, Boolean operators, and their combination.

The selection criteria were: articles in full text, with qualitative or mixed focus and which will approach the experiences of PC adult patients with any underlying disease on hospital discharge, family caretakers and/or relatives on the transition between hospital and home contexts. Of the 12,452 studies found, 14 were included of which three were selected after searching via the snow-ball technique (Table 2).

A review was conducted of the selected databases, seeking relevant titles and abstracts, which were examined to determine their inclusion. The complete texts of the articles selected were read to decide if inclusion criteria applied. From the articles included in this review, information

was extracted about the authors, objective, methodology, participants, country, and principal findings.<sup>14</sup> For the syntheses and grouping by themes of the results of the studies included in this review, the NVivo 10 software (version 10.0.2 for Mac) was used. To guarantee the rigor of the review, during a first phase one of the authors (MAR) selected the potential articles by following

the selection criteria. When doubts emerged on the inclusion of any of the articles, a review was carried out by peers (MAR and CGV) to evaluate the relevance of these studies. In these cases, both authors read independently the texts and included those in which agreement existed with both authors. It is clarified that in no case was there disagreement to include ambiguous cases.

**Table 1.** Key words and combination strategy

Family OR Caregiver*	AND	Perspective OR perception OR experience	AND	Terminal care OR Palliative care* OR end of life	AND	Patient discharge* OR Discharge planning* OR hospital discharge*
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(\*) Descriptor MeSH

**Table 2.** Selection of articles according to source and stage of selection

Stage \ Source	PubMed	ScienceDirect	CINALH	Cochrane Central	OvidJournals	SciELO	Bireme	Search manual
Initial search	3 928	3 781	1 493	1 468	1 476	1	305	37
Selected by title and abstract	14	4	1	0	18	0	1	0
Selected by objectives and results	4	2	0	0	5	0	0	3

## Results

The emerging themes represent the central areas of knowledge on the experiences and principal needs of the dyads in palliative care during the transition from the hospital to the home. Five of the studies took place in the United Kingdom, four in the United States, two in Canada, two in Australia, and one in Sweden. It must be indicated that this review only included those studies where it was identified that patients and caregivers were being treated by a PC attention team, or being cared for in hospices or PC units in general or specialized hospitals. Results of the analysis were grouped into six principal themes: the dyad and its knowledge regarding the diagnosis and prognosis; emotions experienced by the family caretaker and

patient during discharge; effective communication among those involved in caring; education for caring for the person at home; continuous support to the dyad at home, and care overload: social support for the family caretaker.

### The dyad and its knowledge regarding the diagnosis and prognosis

The dyad's need for adequate and honest information of the diagnosis of the disease, its causes, its prognosis, and its progress was a recurrent theme in the studies. In the diagnosis of the disease, several patients and family caretakers were surprised upon discovering that

the disease had no cure or that they were in a terminal phase.<sup>15-17</sup> Regarding the progress of the disease, the family caretakers experienced bewilderment with the quick arrival of the most advanced stages or with the rapid deterioration and the dependence associated to it.<sup>15,17,18</sup> It was, thus, expressed by a caregiver of a patient with Parkinson's: "I knew the patient was deteriorating, but did not expect his dying so soon".<sup>17:733</sup> Also, family caretakers identified that upon treating the prognosis and goals in patient care there was a certain hesitation or lack of knowledge from the professionals to speak of the theme.<sup>19</sup>

With respect to the disease's progress, the studies showed the difficulty of the professionals in addressing themes related to death and end of life. It is, thus, reflected by some family caretakers: "the hardest thing was that I had to tell her (that she was going to die), rather than her hearing it from the physicians".<sup>18:67</sup> Hence, the need to increase the spaces destined by health professionals to talk about the dyad's concerns at the end of life.

### **Emotions experienced by the family caretaker and the patient during the discharge**

The studies selected show ambivalent experiences. On the one side, there was evidence of a lack of inclusion of the family caretaker and everything related to patient care at the intra-hospital level and during the plans for hospital discharge; there was also a limited approach of the anxiety and fears experienced by them in relation to the responsibility of caring for the person at home.<sup>16,17,19-22</sup> Family caretaker referred to the feeling of "not being listened to or included".

For some caregivers, the professionals did not consider their needs,<sup>20</sup> stating that they were not listened to, and having no time to talk and discuss issues of care,<sup>21</sup> and not feeling included in decision-making.<sup>23</sup> Consequently, this made family caretakers more vulnerable to stress and created a barrier for effective communication.<sup>20,21</sup> Expressions like the following are recurrent in the

texts: "I felt I was not included in the team. They are all experts I thought I would be included, but I did not sense it... I was the person who needed help, advice, and everything and I did not feel that I was receiving it".<sup>19:83</sup>

However, positive experiences with the PC teams were also reflected, especially when the family caretakers felt listened to and with the possibility of sharing their experiences and worries with the health team.<sup>23</sup>

For their part, the patients often felt that the application of protocols and paths for action in the in the health institutions overcame the individualized care and the assessment of their real needs.<sup>21,24</sup> Feelings of having been discharged early or without being prepared were frequent complaints within the prioritization of institutional processes over the individuality of the subjects.<sup>20,21,25</sup>

### **Effective communication among those involved with caring**

This category reflects the importance of establishing a two-way flow of information, that is: 1. adequate communication among the health team and patients – caregivers; 2. effective communication between the hospital care team and the professionals in the community setting. In fact, the dyads stated the need to improve communication between the institutional and community levels. Some of the most frequent perceptions were: the lack of communication and interdisciplinary coordination or the use of hospital management systems as a shield to cover the inability or lack of will upon taking action,<sup>21</sup> the scarce implication of patients and relatives with community PC networks<sup>26</sup>, poor coordination in the continuity of care,<sup>15,16,19,25</sup> fragmentation in care out of the hospital, and scarce community support.<sup>16</sup> Additionally, honesty in communication was especially valued by the dyads; a concrete example is the importance of communicating in clear, delicate and simple manner about the proximity of death.<sup>18,24</sup> However, it also became

evident that it was important to measure correctly how much the families already know and how much they want to know, given that in some cases, providing too much information may generate tension and anxiety in the dyad when it is not furnished at the right moment.<sup>18,22</sup>

Besides, scarce communication or its late start and the use of difficult-to-understand language may also entail difficulties for the dyad.<sup>15-17,19,23,24</sup> Some problems derived from insufficient communication were: difficulty in handling certain situations at home,<sup>18</sup> inadequate understanding among the different levels of care, confusion in recognition of the professional roles,<sup>19</sup> and the range of services provided by the health institutions or offered in the community.<sup>16,17,23</sup> The following interview extract reflects the value granted by the family caretakers when communication is good: "He (the physician) answered questions in my language and said things in a way we could understand... He spent time explaining to us".<sup>27,31</sup> Coordinated, assertive, honest, continuous, and simple communication has been identified between the health professionals and the dyads as substantial for the patient's discharge to be of quality.

### **Education for caring for the person at home**

The different studies underscored the needs for education of the family caretakers to successfully achieve the tasks of caring at home. These needs included: education in managing symptoms,<sup>15-18,22,24,28</sup> management of medications,<sup>16,18</sup> assisting patients in daily life activities,<sup>16,19,22,28</sup> resources available in the community<sup>16,19</sup>, and addressing emergencies at home.<sup>28</sup> Due to the scarce information provided on occasions by health professionals or to its generalization during hospital discharge,<sup>16,24</sup> family caretakers identified problems related to moving the patients at home, ignorance of the diet they could supply,<sup>22,23</sup> readjustments of medication dosage, uncontrolled symptoms,<sup>28</sup> and feelings of uselessness and confusion.<sup>15,18</sup>

### **Continuous support to the dyad at home**

The needs for support after discharge included: having professionals available on call in case of doubts or emergency, providing professional care, and monitoring in the community.<sup>15,17-22,26</sup> In relation to the need for contact with the PC team, several dyads stated not having someone to call in case of having doubts about the care for a loved one.<sup>18,20</sup> Some studies, on the contrary, showed quality telephone follow up of the dyads and even described the possibility of expanding access to professionals to 24 hours through information technology tools.<sup>17,19</sup>

With respect to monitoring at home by a health professional, evidence demonstrated that it favored management of medication and control of symptoms, diminishes patient and caregiver uncertainty, facilitates discussion around end-of-life themes, provides nutritional advice, helps with handling technical equipment, and gives individuals a sense of security and supervision in the care labor.<sup>15,17,19,20,22,23,27</sup> Lastly, the dyads who did not receive support after hospital discharge described learning how to handle the sick person at home through trial and error,<sup>28</sup> delays when seen by reference personnel in the community due to their unawareness,<sup>15,16,26</sup> expecting little from the home healthcare<sup>22</sup>, and neglect by the attending hospital.<sup>21</sup>

### **Care overload: social support for the family caretaker**

Home care can have a big impact upon family caretakers. Among the principal problems identified, there are loss of employment or reduction of the hours destined to caring for the sick person,<sup>27</sup> physical-emotional exhaustion, onset of diseases,<sup>15,17,26</sup> lack of effective coping with the disease, little time for themselves,<sup>21</sup> and increased dependence on the role of the caregiver.<sup>15</sup> The following extract evidences the experience of a caregiver: *I feel I am in prison here with him and every day is like... the previous one.*<sup>16:931</sup>

The problems described previously are part of the care overload. As expressed by the dyads, there was a need for: access to anticipated social support or description of how to have access to it,<sup>19,20,24,27</sup> education in self-care,<sup>15,22</sup> favor leisure time for the caregiver,<sup>22</sup> and provide support in the disease's economic burden.<sup>16</sup> Also, the relatives demand increased social-health spaces that allow for a break and the wellbeing of caregivers, while also securing quality attention for the sick person.<sup>15,22</sup>

## Discussion

The findings of this review suggest that the transition experience of palliative care from the hospital to the home for patients and their family caregivers implies intense emotions, often negative. It should be mentioned that although it is true that patients and caregivers in palliative care have positive experiences of the attention received, as shown in this article, this review has mainly focused on not very positive experiences reported by patients and relatives to identify aspects of improvement in healthcare at the end of life. In this sense, from this review improvement proposals are derived in the following areas. On the needs for information of the dyads, it is identified that having knowledge about the disease, its prognosis, progress; and that the information be given in clear, understandable, and honest manner favors the link between the dyad and the health professional, and also diminishes anxiety and uncertainty in the dyad. In these same terms, Waldrop *et al.*,<sup>29</sup> indicate that giving information about the disease and its prognosis implies, besides what has been mentioned, being able to help patients and families to understand and/or accept the terminal process.

As with information, inclusion of family caretakers within the plan for hospital discharge and as part of the care team is essential. Bearing in mind their points of view, opinions, strengths, weaknesses, and their global experience as caregivers, permits empowering their role. According to

various investigations, empowering the caregiver translates into a better experience of homecare for the dyad,<sup>30-32</sup> better control of the symptoms, diminished hospital readmissions, satisfaction with the care team,<sup>32,33</sup> decreased feelings of abandonment, and reduced health costs.<sup>29,35-37</sup>

Improving the communication during the transition from the hospital to the home was a recurrent theme and of concern for the dyads, who expect assertive, true, permanent and transversal communication in all contexts (hospital, home, community) and which, likewise, involves the professionals in the institution, patients, family caretakers, and health professionals of reference in the community.<sup>38,39</sup> In this respect, several investigations state that adequate communication among all care levels and among the subjects involved improves knowledge and access to the health services available, favors education for caring, facilitates identification of the individual and family needs,<sup>35,36,40,41</sup> guarantees a safe transition for the dyad between the hospital and the home,<sup>36,42</sup> and – lastly – adequate follow up in the home.<sup>41,43,44</sup>

From this review, we may also derive the need to continue implementing and evaluating cares that are being valued as very positive by patients and family caretakers for a positive transition between the hospital and the home. Among others, they highlight the following: education of the dyad during hospital discharge,<sup>35,38,45</sup> telephone follow up,<sup>46,47</sup> homecare teams,<sup>48,49</sup> and support groups of patients and caregivers.<sup>30,31</sup> Regarding these types of support, Stajduhar *et al.*,<sup>50</sup> comment that the nature of the experiences of the dyads in PC can vary according to the structure of the health systems and of the social services, of access to services, and of the types of support available.

In fact, one of the limitations of this review is the inclusion of studies conducted in countries with different health policies, which undoubtedly influence upon the experiences narrated by patients and relatives in palliative care. Also, the inclusion of studies with patients attended in different health contexts, like hospices or PC

units in general hospitals may lead to a different experience of the transition from the hospital to the home. Another one of the limitations of this review is the inclusion of studies that presented retrospectively the experiences of the participants once they were in their homes and sometimes months after the hospital discharge. This circumstance could limit the knowledge of the concrete needs of the participants during the transition from the hospital to the home after hospital discharge.

The conclusion of this study is that the need exists to improve healthcare, and specifically in Nursing, in the different stages of the transition from the hospital to the home. It seems necessary to implement new interventions that improve, among other issues, communication between the professional and the user in palliative care services, preparation and education of the family caretaker for caring at home, offer of community support networks, and early address of the grief or resolution of conflicts. It is true that the interventions mentioned are necessary during any stage of healthcare; however, during the final stage of life these gain special relevance, for users and for healthcare professionals. In this sense, further studies are proposed to assess the effectiveness of new interventions from the palliative care teams that cover the physical, emotional, and spiritual needs of the patient at the end of life during the transition from the hospital to the home, as well as emotional, educational needs and the need to care for the caregiving relative.

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