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# **Patient and family experiences of palliative care in hospital: what do we know? An integrative review**

**Jackie Robinson** *School of Nursing, University of Auckland, New Zealand; Auckland District Health Board, Auckland, New Zealand*

**Merryn Gott** *School of Nursing, University of Auckland, Auckland, New Zealand*

**Christine Ingleton** *School of Nursing and Midwifery, University of Sheffield, Sheffield, UK*

## **Abstract**

### **Background**

Understanding the experiences of hospital admissions for people with a life limiting illness, and their families is essential in understanding the role acute hospitals have in providing palliative care.

### **Aim**

The aim of this review is to synthesise current evidence regarding the experience of palliative care in an acute hospital setting from the perspectives of patient and family.

### **Design**

An integrative review was completed using standard processes followed by a process of data extraction and synthesis.

### **Data Sources**

Using pre-defined search terms, literature was sourced from five electronic databases between January 1990 and November 2011. Reference lists from relevant articles were cross checked and pertinent journals hand searched for articles.

### **Results**

Five recurring themes were identified from the synthesised data: symptom control and burden, communication with health professionals, decision making related to patient care and management, inadequate hospital environment and interpersonal relationships with health professionals.

### **Conclusion**

This review has identified that, largely as a result of study design, our knowledge of patient and family experiences of palliative care in an acute hospital remains limited to discrete aspects of care. Further research is required to explore the total patient and family experience taking into account all aspects of care including the potential benefits of hospital admissions in the last year of life.

### **Keywords**

Palliative care, hospitalisation, patient admission, patient satisfaction, professional-family relations

### **Background**

In most developed countries, acute hospitals play a significant role in palliative care provision. Evidence shows that at any one time 13-36% of hospital inpatients meet the criteria for palliative care need.<sup>1-3</sup> Hospitals are often the setting where a life limiting diagnosis is made and where patients present when symptoms develop or when they are not well managed.<sup>4</sup> Furthermore for people with illnesses such as chronic obstructive pulmonary disease and congestive cardiac failure, hospitals provide episodic care over many years for illness exacerbations during which death could occur.<sup>5</sup> In most developed countries, hospitals are also the setting in which most people will die. A recent comparison of institutional deaths across 45 countries concluded that, for half of those countries, more than 54% of deaths occur in hospital.<sup>6</sup>

One factor that is impacting upon the role of the acute hospital in palliative care is the increasing use of technology. Wide-spread use of life supporting technologies that keep people alive who would otherwise die within a foreseeable, but usually uncertain period of time, has radically transformed the life expectancy of some people with a life limiting illness.<sup>7</sup> Like other areas of health care, palliative care has embraced the advancement of health technologies and it is now common place to offer, what some may consider as being invasive,<sup>8</sup> interventions to achieve symptom control and improve quality of life whilst at the same time, in some instances, extending life. Many of these interventions can only be provided in a hospital environment and may impact on the way in which palliative care is delivered.<sup>9, 10</sup>

As a result of the global economic crisis, governments are searching for ways to make limited public health spending go further. Studies looking at inappropriate or avoidable admissions amongst patients with palliative care needs and economic analyses of hospital use in the last year of life are being carried out to ensure that health resources are being used wisely.<sup>11, 12</sup> In addition patient and family preferences to be cared for at home or in a hospice rather than in a hospital setting, have been well established in the literature.<sup>13, 14</sup> A systematic review of the literature by Brereton et al.<sup>15</sup> has demonstrated the inadequacies of the hospital environment in providing palliative care. These factors are becoming key drivers at a policy level to reduce acute hospital admissions amongst patients with a life limiting illness. However what is missing in this debate is how patient and families experience palliative care in hospital.

Understanding the experiences of hospital admissions for patients with a life limiting illness, and their families is essential in understanding the role acute hospitals have in providing palliative care. For the purpose of this review palliative care has been defined, in line with the Canadian Hospice Palliative Care Association definition, as an approach that “aims to relieve suffering and improve the quality of living and dying” and is “appropriate for any patient and/or family living with, or at risk of developing, a life threatening illness due to any diagnosis, with any prognosis [and] regardless of age.”<sup>16</sup>

### **Aim**

The aim of this review is to synthesise existing international evidence regarding the experience of palliative care in an acute hospital setting from the perspectives of patient and family. Synthesising literature in this way helps to provide a more comprehensive understanding of a particular topic to inform future research, practice and policy initiatives.<sup>17</sup>

### **Design**

An integrative review was completed in keeping with the process outlined by Whitemore and Knafel.<sup>17</sup> A review of the literature was undertaken followed by a process of data extraction and synthesis. Quantitative and qualitative studies that provided data regarding the experiences of palliative care in a hospital setting from the perspectives of patients and families were included.

### **Search process**

Using pre-defined search terms (see Table 1) Medline (Ebsco), CINAHL, EMBASE, Cochrane and PsycInfo were searched for studies published between January 1990 and November 2011. The search was carried out by JR with assistance from a specialist librarian. Appropriate wildcards were inserted to search for word ending truncations where necessary. Reference lists from relevant articles were cross checked. The following journals were hand searched for relevant articles between 1990 and 2011: *Palliative Medicine*; *Journal of Palliative Medicine*; *BMJ Supportive and Palliative Care*; *Journal of Pain and Symptom Management*; *International Journal of Palliative Care Nursing* and *BMC Palliative Care*. Details of the study identification and selection process are shown in the PRISMA flowchart (figure 1).

**Table 1 Search terms used in electronic database search**

	Search Terms
Palliative Care	Palliative care; supportive care; terminally ill; hospice care; end of life care
Hospital	Hospital admission; readmission; hospitaliz(s)ation; length of stay
Patient	Patient experience; patient perspective; patient satisfaction; patient preference
Family	Family experience; family perspective; family satisfaction; family preference

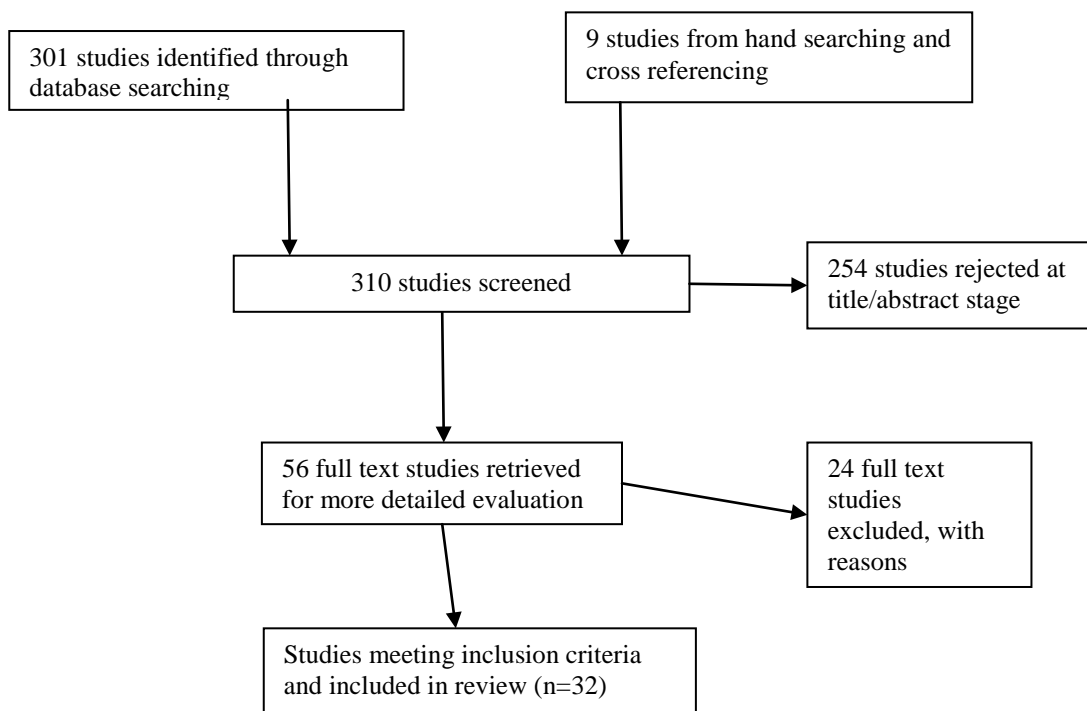
A rigorous approach to the search process identified 301 studies which were examined for relevance to the review topic. Studies had to refer to the experience of care in hospital amongst patients with palliative care needs and/or their family and include the views of patients and/or families. Studies also had to refer to an adult population over the age of 18 years old and be available in English. Studies prior to 1990 were excluded as it was felt that palliative care as an integral component of care in an acute hospital setting was less well developed prior to that time.<sup>18</sup> In addition studies conducted in the emergency department (ED) and intensive care unit (ICU) were also excluded because there are unique issues related to patient and family care that are specific to these clinical environments. A summary of inclusion and exclusion criteria can be found in table 2.

**Table 2 Inclusion and exclusion criteria**

Inclusion	Exclusion
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Written in English language	Written in languages other than English
Papers focusing on patient and family views	Papers focusing on health professional's views and case reviews
Palliative care in hospital	Palliative care in ICU or ED
Palliative or end of life care	Not focusing on palliative or end of life care
Papers after 1990	Papers before 1990
All types of studies	

Study selection was conducted in a systematic sifting process over three stages: title, abstract and full text. At each stage, studies were rejected that definitely did not meet the inclusion criteria. Using the title and abstract each paper was assessed by JR and rejected if they did not meet the inclusion criteria. Those that met the criteria were then independently assessed by JR and one of the other authors; in cases where there were disagreements of inclusion, consensus was reached by discussion. All literature was retained as background information. Overall 32 studies satisfied the inclusion criteria (see table 3).



**Figure 1 PRISMA flow chart**

## Data Evaluation

Evaluating the quality of studies in a systematic review relies on a narrow sampling frame and similar research designs. In the case of integrative reviews, the inclusion of both qualitative and quantitative studies makes the process of data evaluation difficult<sup>17</sup> and may provide little value. Furthermore, palliative care poses its own specific challenges to systematic review methods; the research base is relatively limited and the complexity of methodological and ethical issues result in an evidence base largely unsuitable for traditional forms of review and synthesis.<sup>19</sup> For these reasons, data evaluation was not undertaken in this review.

## Data Extraction and Synthesis

All data relevant to patient and family's experiences of hospital admissions were examined using a 4 step process to identify key themes as outlined in table 3. The data extraction process was reviewed by all authors and agreement sought on the identification of key themes.

Table 3 Process of data extraction and synthesis

Step	Process
Familiarisation with the data	Immersion in the data by reviewing each study thoroughly, extracting and tabulating qualitative and quantitative data.
Generation of initial codes	Focusing on data related to the review question (patient and family experience) codes were manually attached to the data.
Searching for themes	Codes were sorted into overarching themes within the tabulated data.
Identifying themes	Potential themes were refined and discussed with MG and CI. Themes were discarded if there was not enough data or the data was too diverse.

Adapted from Braun and Clark<sup>20</sup>

## Results

Through a search of electronic data bases, 301 studies were identified with a further nine found through hand searching of relevant journals. Of the 310 studies screened by title and abstract a total of 56 full text studies were retrieved for further review. Twenty four studies were excluded because they did not meet the inclusion criteria. A total of 32 studies satisfied the inclusion criteria. (See table 3). They consisted of a mixture of qualitative (n=8), quantitative (n=20) and mixed methods studies (n=4).

Ten studies related to patients with cancer,<sup>21-30</sup> two related to patients with stroke<sup>31,32</sup> and one with chronic obstructive pulmonary disease.<sup>33</sup> Four<sup>34-37</sup> studies did not state diagnosis. Two papers used two diagnostic groups in the same study; one compared patterns of care for patients with non small cell lung cancer with severe COPD.<sup>38</sup> The second study compared experiences of patients who died with end stage dementia to those who had died with congestive heart failure.<sup>39</sup> The remaining thirteen studies included patients from a variety of different diagnostic groups.<sup>40-52</sup>

Seven studies used data from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT).<sup>38, 40, 42, 44, 50-52</sup> The objective of SUPPORT was to “improve end of life decision making and reduce the frequency of a mechanically supported, painful and prolonged process of dying”.<sup>51</sup> (p1) Data were collected across five teaching hospitals in the USA.

The perspectives of bereaved families were captured in 17 of the studies.<sup>21-25, 29, 32, 36, 37, 39-41, 43, 47-50</sup> The time from death to data collection ranged from 4 weeks to 2 years. Four studies included the views of both patients and families.<sup>26, 28, 31, 46</sup> Two studies sought the family’s perspectives to describe their experience of having a family member in hospital in relation to such things as decision making and communication with health professionals. In those studies that collected data directly from patients there was variation in how participants were identified as being ‘palliative’ or near the end of their life. The majority based this on diagnoses rather than estimated prognosis.

Seven studies compared palliative care across a number of different care settings including hospital.<sup>22, 23, 29, 32, 35, 48, 49</sup> Two studies specifically compared palliative care in a hospital



setting with care provided in a hospice.<sup>21, 29</sup> One study compared patient and family experiences of care in hospital, home and aged residential care.<sup>49</sup>

Five recurring themes were identified from the synthesised data:

- a) Symptom control and burden
- b) Communication with health professionals
- c) Decision making related to patient care and management
- d) Inadequate hospital environment
- e) Interpersonal relationships with health professionals

### **Symptom control and burden**

Of the papers identified, nineteen examined patients and families experiences of care in relation to symptom control and/or symptom burden in the acute hospital setting. Two papers concluded that both patients and families rank control of pain and other symptoms as extremely important yet identified however it is an aspect of care they are consistently most dissatisfied with.<sup>33, 46</sup> Furthermore, two papers reported that both patients and families will prioritise relief of pain or maintaining comfort over prolonging life.<sup>38, 47</sup>

Overall the reviewed evidence indicates that hospitalised patients with a serious life threatening illness report a high symptom burden. In a study by Desbiens et al.<sup>44</sup> nearly half of patients interviewed reported having one or more symptoms of at least moderate severity occurring at least half the time or of extreme severity of any frequency. Pain, dyspnoea, anxiety and depression caused the greatest symptom burden. Family also reported a high level of symptom burden for patients who were dying in hospital. For example, in one study, more than 80% of family participants reported that their family member frequently experienced serious pain, dyspnoea or affective distress (confusion, depression or emotional distress) during their final hospital admission.<sup>43</sup>

Two studies compared family's experiences of their family member's symptom control in hospital and hospice. Addington-Hall and O'Callaghan<sup>21</sup> found that significantly more patients had pain controlled 'all of the time' in hospice compared to hospital (81% c/t 39%). However, there were no differences found in the prevalence of pain or the distress it caused. By contrast Seale and Kelly<sup>25</sup> reported that relief of pain and other symptoms was achieved in

the majority of patients in hospital with no significant differences in the effectiveness of treatments across the two settings.

Dissatisfaction with pain and symptom control from the perspective of both patients and families featured highly in the reviewed studies. Desbiens et al.<sup>52</sup> found that 50% of seriously ill patients reported extreme or moderate severe pain at least half the time and 15% were dissatisfied with pain control. In the study by Lynn et al.<sup>50</sup> almost 40% of conscious patients were reported by surrogates as having severe pain and dyspnoea in the last 3 days of life and three quarters of these families found this distressing.<sup>50</sup> The impact of witnessing a patient in pain was significant for families and became a focus of distress when left uncontrolled.<sup>36</sup>

### **Communication with health professionals**

Patient and families experiences of communication with health professionals in the acute hospital setting was a dominant theme in the review, featuring in seventeen studies. The disciplinary background of the health professionals involved were not stated in the majority of studies reviewed. Most studies drew upon bereaved families experiences of interactions with health professionals (n=14). Although there were some reports of positive experiences, across the reviewed studies the overriding view from both patients and families was that the standard of communication with health professionals in the acute hospital setting is poor.

Patients and families criticised the quality and type of information received from health professionals with reports of difficulties in understanding the language used.<sup>48</sup> This was particularly so for conversations involving prognosis. Families also felt that they were not always kept informed of the patient's condition. As a result death was typically perceived as happening 'suddenly'. The amount and type of information provided by health professionals was reported in four studies to not be tailored to individual preferences. Doctors' 'talking over' unconscious patients was identified as being particularly concerning to families who feared that the patient was unable to express their preference for information about prognosis and might be told something they did not want to know.<sup>31</sup>

A common theme related to the way in which information was communicated to patients and families in hospital; this was reported to often be done badly particularly when health

professionals were giving “bad news”.<sup>22, 24, 25</sup> Furthermore in one study participants felt that staff lacked the skills required to have these difficult conversations.<sup>24</sup>

Studies reported that patients and families perceived busy staff as being unavailable.<sup>36</sup> This sense of unavailability was exacerbated further when visiting families experienced difficulties finding a doctor or nurse who could provide an update on the patient’s condition. Constantly having to seek out staff to get updated information about the patient coupled with the fact that staff rarely approached them to ask if there was anything they needed to know, left family feeling dissatisfied.

### **Decision making related to patient care and management**

In a study by Young et al.<sup>32</sup> being involved in decision making about patient care and management was found to be a predictor of family satisfaction in the last three days of life. Both patients and families rated being “involved in decisions regarding treatment and care” as an important element of end of life care.<sup>46</sup>

According to the studies reviewed the majority of patients and families felt that they were involved in decisions related to patient care and treatment as much as they wanted to be.<sup>40</sup> Heyland et al. found that over 80% of participants, including both patients and families, were satisfied or highly satisfied with how they were involved in decision making during a hospital admission.<sup>46</sup> Addington-Hall et al.<sup>21</sup> found that families were more likely to report they had been involved in decisions about the patients care in hospice than in a hospital setting.

A number of factors were identified in the reviewed studies as impacting on a family’s ability to contribute and participate effectively in end of life decision making within hospital. This included a lack of information about care and treatment options, lack of knowledge about the patient’s condition, uncertainty regarding prognosis, difficulties in obtaining information and receiving insufficient explanations about what staff were doing and why.<sup>31</sup>

Two studies reflected on how families had difficulties making decisions which they perceived to be a matter of “life or death” for the patient, even when death was inevitable.<sup>31, 37</sup> In these situations families felt that using health statistics related to the patient’s chances of recovery was not helpful. Feeling rushed into making these decisions increased the family’s distress. Payne et al.<sup>31</sup> in a study on end of life issues in stroke found that a families perception of

what constitutes a “good death” influenced their level of comfort in making decisions about resuscitation and withdrawing treatment.

### **Inadequate environment**

In the papers reviewed, the hospital environment was criticised as being noisy and busy and an inappropriate place to die.<sup>23, 25, 36</sup> The perception of busyness within the hospital resulted in patients and families feeling as if they were ‘lost in the numbers’ which left them feeling unvalued and uncared for.<sup>35</sup>

In a study by Dunn and Sullivan,<sup>36</sup> family felt that a lack of privacy impacted on their ability to have conversations with patients at a time when they wanted to talk about personal issues. In addition families commented on a lack of interview rooms to talk privately to staff. As a result families felt self conscious at expressing strong emotion in public places when having conversations about end of life.

The lack of single rooms for dying patients was a concern for families who worried about the dying patient being disturbed by agitated and confused patients in multi-bed rooms. Family’s also expressed concerns for recovering patients in the room being distressed by watching someone dying.<sup>31</sup>

In studies by Rogers et al.<sup>24</sup> and Spichiger<sup>27</sup> hospital bureaucracy was seen as being a barrier to effective care. Admitting procedures did not accommodate the care required to keep a patient comfortable<sup>24</sup> and visiting hours were inflexible causing families to feel that they were in the way if they were present outside visiting hours. Patients were moved frequently within and between wards and at a time when families perceived them as being too ill to be moved.<sup>36</sup>

### **Interpersonal relationships with health professionals**

In the papers reviewed patients and families were more inclined to remember those health professionals who took the time to show empathy and kindness. Some families felt that nurses did not take the time to show empathy towards the patient and were insensitive to families who wanted to stay with the patient.<sup>53</sup> This was particularly difficult for those families who were the patient’s main caregiver prior to the hospital admission. The lack of

integration of a family's care giving role by hospital staff led to feelings of helplessness in one study.<sup>36</sup>

Family perceived busy nurses as not having time to spend with patients to find out what was important to them. In a study by Spichiger<sup>28</sup> this left patients and families feeling forgotten and not cared for. In contrast when families felt cared for it was often in response to staff who were attentive to their needs, appeared approachable and friendly and checked in frequently with family to make sure they had what they need.

In the study by Young et al.<sup>32</sup> there was a high correlation with patient satisfaction and being treated with respect and dignity.

## **Discussion**

This integrative review provides an overview of international evidence regarding patient and family experiences of palliative care in a hospital setting. The evidence suggests that patients experience a significant symptom burden with poor management of symptoms while in hospital. The hospital setting is considered to be an inappropriate environment for dying patients, being too busy and noisy and lacking privacy. Being involved in decision making related to patient care and management can be difficult for families and a number of factors impact on their ability to do this effectively. Furthermore patients and families experiences of communicating with health professionals and establishing a positive relationship are challenging in the hospital setting.

Differences in patient and family experiences of palliative care with different diagnoses have been reported in previous research. Those with a non cancer illness are more likely to experience repeated hospital admissions<sup>54</sup> and less likely to receive input from hospice palliative care services compared to those with cancer<sup>55, 56</sup> despite the fact that their palliative care needs can be significant.<sup>57</sup> The studies identified by the review included patients with a wide range of diagnoses and were at varying stages of the illness trajectory, although most studies did not report details of illness stage. This makes it difficult to come to any conclusion regarding differences in patient and family experiences of hospitalisations by diagnosis or prognosis.

Moreover a number of design issues were identified in the studies reviewed and as a result we only have a limited understanding of the overall experiences of patient and family.

Firstly, the use of satisfaction based studies limits our understanding of the patient and families overall experience of care in hospital. Whilst satisfaction surveys are used widely to elicit the views of service users they often use closed questions addressing the priorities of the service provider or researcher rather than the service user. In addition, expectation is considered to be a major determinant of satisfaction and is largely related to an individual's perceptions of the benefits of care and the extent to which these meet their expectations.<sup>58</sup> However this was not addressed in any of the studies

Secondly, using symptom prevalence as an indicator of patient's overall experience of palliative care in hospital is limiting. It would not be unusual to find patients in a hospital setting with a high symptom burden during a period of acute illness and in fact this is often what precipitates an admission to hospital.<sup>4</sup> In view of the fact that the hospital setting is often criticised as being poorly prepared to provide adequate symptom control at the end of life<sup>59, 60</sup> exploring the effectiveness of symptom management may be more useful.

Thirdly, using patient proxies provides a limited understanding of patient experience. Fifteen studies in the review used patient proxies to a varying degree as a way of understanding the patient's experience of care in hospital. This included information regarding the severity of symptoms such as pain and dyspnoea. Whilst data collected after death from proxies are a vital source of information in palliative care, the validity of reporting has been questioned. Factors such as the previous relationship with the patient, caregiver burden and an individual's beliefs and expectations of care can impact on the congruence between patient and proxy reporting. Proxies have been shown to be reliable reporters on the quality of services and on observable symptoms, however agreement is poorer for subjective symptoms such as pain, anxiety and depression.<sup>61</sup> Accuracy of recall is influenced by the period of time between the experience and the recollection of the experience. In those studies reviewed that used data collected from family, all but one study surveyed families who were bereaved. The time from death to the collection of data varied considerably and ranged between 1 month and 2 years. Retrospective data collection from families post bereavement has been shown to change significantly over time particularly in regards to symptoms such as pain and depression.<sup>62</sup>

Finally, comparing experiences of hospital care with that which is provided in other settings such as hospice may not be that useful. Some aspects of hospital care are unlikely to ever meet the same standard as hospice care. For example, the homely environment provided by hospices is difficult to emulate in a hospital setting.<sup>15</sup> Multi bedded rooms are common place and patient turnover is high. Providing an appropriate level of privacy, cleanliness and easy proximity to family and friends has been identified by patients, families and health professionals as being important in hospital end of life care<sup>15</sup> and yet the hospital continues to be cited by patients and families as an inappropriate setting primarily because of its limitations in providing these aspects of care.

### **Limitations**

This integrative review synthesises the current international evidence base regarding patient and family experience of palliative care in an acute hospital setting. Electronic search, retrieval and review strategies were used however the search is subject to some limitations. Data bases were limited to English and due to resource limitations a search of the ‘grey literature’ was not carried out. As a result some studies may have been missed.

### **Conclusion**

Despite the fact that people express a preference to be cared for and die at home or in a hospice, hospitals continue to play a significant role in providing palliative care. In many countries the majority of people still die in a hospital setting and many will be admitted to hospital during the last year of their life.

This review has identified that, largely as a result of study design, our knowledge of patient and family experiences of palliative care in an acute hospital remains limited to discrete aspects of care. Further research is required to explore the total patient and family experience taking into account all aspects of care including the potential benefits of hospital admissions in the last year of life.

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### **Conflicts of interest**

No conflicts of interest to declare.

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