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journal homepage: www.elsevier.com/locate/healthplace

The acute hospital setting as a place of death and final care: A qualitative study on perspectives of family physicians, nurses and family carers



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ARTICLE INFO

Article history:

Received 18 July 2013

Received in revised form

9 January 2014

Accepted 1 February 2014

Available online 25 February 2014

Keywords:

Place of death

Location of death

Hospitals

Palliative care

Terminal care

ABSTRACT

While the focus of end-of-life care research and policy has predominantly been on 'death in a homelike environment', little is known about perceptions of the acute hospital setting as a place of final care or death. Using a qualitative design and constant comparative analysis, the perspectives of family physicians, nurses and family carers were explored. Participants generally perceived the acute hospital setting to be inadequate for terminally ill patients, although they indicated that in some circumstances it might be a 'safe haven'. This implies that a higher quality of end-of-life care provision in the acute hospital setting needs to be ensured, preferably by improving communication skills. At the same time alternatives to the acute hospital setting need to be developed or expanded.

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1. Introduction

The debate about the appropriateness of different care settings as a place of final care and death started at least two decades ago, but the issue remains alive and relevant to this day (Bowling, 1983; Costantini, 2008). Following a rising proportion of people dying in hospital throughout the 20th century, the proportion of hospital death has slightly decreased in several countries during the last decade, e.g. in Belgium from 55.1% to 51.7% between 1998 and 2007, indicating a potential shift in end-of-life care from the hospital towards other locations (Houttekier et al., 2011; Wilson et al., 2002; Wilson et al., 2009). However, despite national policies aimed at increasing home death, the proportion of people dying in a hospital setting remains persistently high (Broad et al., 2012; Gomes et al., 2012; Cohen et al., 2008; Grande, 2009).

Because home has been consistently reported as the preferred place for end-of-life care in many populations around the world, end-of-life care policies generally support the home as the most desirable place of death (Grande, 2009; Gomes et al., 2012;

Agar et al., 2008); dying at home is considered to be a condition for a 'good death', and is often assumed to be the gold standard (Paddy, 2011).

On the other hand, some studies have suggested that a preference for the home setting as the place of final care and death might change in favour of hospital as death approaches (Agar et al., 2008; Gerrard et al., 2011). Another study suggests that, while older people might prefer a home death in ideal circumstances, a relatively large proportion can imagine that they would choose to be cared for elsewhere when dying if circumstances were not ideal (Gott et al., 2004). Reasons such as having limited informal care and preferring safe professional care can lead to patients preferring not to die at home (Thomas et al., 2004; Wilson et al., 2013).

Furthermore, it has been suggested that the acute hospital setting is perceived to be inadequate and too medicalized to provide proper end-of-life care (Borbasi et al., 2005). It is a place where death might be perceived as a technical or medical problem and it has been suggested that there is an inclination in the acute hospital setting to engage in more aggressive treatment and to routinely use all available technological options (Clark, 2002; Al-Qurainy et al., 2009; Willard and Luker, 2006). Moreover, achieving a comfortable or homely environment may prove to be difficult in such a clinically focused setting (Gardiner et al., 2011; Brereton et al., 2012).

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In Belgium, 25 palliative care networks, each covering around 300,000 inhabitants, generally coordinate the intervention of palliative care services and integrate them into the regular health care system (Desmedt et al., 2011; Keirse et al., 2009). Family physicians, home care and nursing home nurses have a pivotal role in providing end-of-life care outside of the hospital, while hospital physicians and nurses provide such care within the hospital setting. All professional caregivers, as well as family caregivers, can be supported and assisted by specialist palliative care providers, who are part of such a palliative care network. Furthermore, there are 51 palliative care units that are generally located on a hospital campus, although they are considered independent of the acute hospital setting (Keirse et al., 2009). Given there are only 379 such palliative beds in Belgium, which is insufficient in view of the palliative care demand, every acute hospital also has an intramural palliative support team (Desmedt et al., 2011). Given their pivotal role in end-of-life care and end-of-life hospital admission experiences, professional and family caregivers' perspectives are considered essential in this study.

Like the relevant health care policies, most research has been focused mainly on the home setting as the ideal place of death. As a result, little is known about how the acute hospital setting is perceived as a place of final care or place of death. Considering that many people eventually die within this setting, an adequate understanding of the perceptions and experiences of the acute hospital setting as the place of final care and death is important as this might indicate areas for improvement regarding the quality of end-of-life care provision within the hospital.

The aim of this study is to explore the perspectives of family physicians, nurses from different care settings (home, nursing home and hospital) and family carers of those who died in an acute hospital setting concerning the acute hospital setting as a place of final care or death.

2. Methods

In order to be able to comprehend adequately the experiences and opinions of family physicians, nurses and family carers and to develop an understanding about their perceptions of the acute hospital as a place of final care and death a qualitative design was considered most suitable (Flick et al., 2004). Eight focus groups were used, three with nurses ($N=23$) and five with family physicians ($N=39$) and 17 semi-structured interviews with bereaved family carers were conducted.

2.1. Focus groups

Focus group discussions were considered to be the best approach to explore the opinions and experiences of nurses and family physicians, given its meaningful process of sharing and comparing (Morgan, 1998). Participants were purposively selected from different care settings (nursing home, hospital or home setting) for the nurse focus groups in order to maximize variation in experience and background, as shown in Table 1 (Morgan et al., 1998). To recruit

Table 1
Focus group characteristics.

Focus group		N1	N2	N3	FP1	FP2	FP3	FP4	FP5	Total
Care setting	Family physician				7	5	9	13	5	39
	Nursing home	2	1	7						10
	Nurse									
	Hospital Nurse	4	4							8
	Home Care Nurse	2	3							5

N: Nurses; FP: Family physicians

family physicians, existing peer-review groups for family physicians were invited to participate via email and five from Flanders and Brussels were planned because of their availability. Nearly 97% of all family physicians in Belgium are affiliated to such a peer-review group and are obliged to attend at least two out of four meetings per year for accreditation, where they discuss aspects related to family physician practice (RIZIV, 2008). The data used in this study were collected in the context of a wider study exploring the justifications given for hospital admissions at the end of life, for which a topic guide was developed by the research team and slightly modified after each focus group. After given their written informed consent, participants were asked about their experiences and opinions concerning the acute hospital as a final place of care or death and end-of-life hospital admissions. Next, a discussion was generated about what, when and why an end-of-life hospital admission would be appropriate or justified, by using vignettes describing three different cases. Lastly, participants had to identify key factors that would justify an end-of-life hospital admission. During focus group discussions, participants were encouraged to express their opinions and experiences concerning the acute hospital as a setting for dying patients. For each focus group the number of participants and their professions are shown in Table 1.

2.2. Interviews

Additionally, the perspectives of family carers of people who had died within an acute hospital were included using semi-structured interviews. We anticipated that discussing their experiences might provoke emotional reactions and therefore would most suitably be explored in depth through face to face interviews (Marshall and Rossman, 2010; Flick, 2002). These family carers were recruited using purposive and snowball sampling, which was mainly focused on including different disease trajectories, as shown in Table 2. In recruiting respondents it was considered important that they had cared for a family member or friend with a chronic life-limiting disease (i.e. cancer, organ failure or dementia) during the last phase of life and who had died in a hospital between three months and two years before the interview. Several health care organizations were contacted who informed their professional caregivers and placed announcements in their newsletters or on their websites, encouraging potential respondents to contact the researchers (TR), while family physicians and nurses who had participated in focus groups and other interview respondents were also asked to contact potential family carers. When inclusion criteria were met, an interview was scheduled. As shown in Table 2, respondents were either a partner, sibling, son or daughter.

All interviews were conducted by one researcher (TR) and lasted around 45 min, using a topic list, which was developed by the research team and altered when necessary. Respondents were asked about their opinions of and attitudes towards the acute hospital as a place of final care and death and about their experiences concerning hospital

Table 2
Family carer characteristics.

Family carer relationship to patient	Illness of patient family carer took care of		
	Cancer	Organ failure	Dementia or frailty
Partner	FC2, FC8, FC9	FC5, FC12, FC16, FC17	FC10, FC14, FC15
Sibling	FC3		FC7
Son	FC4		FC6
Daughter	FC1, FC13	FC11	

FC: Family Carer

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