

The Family Physician's Perceived Role in Preventing and Guiding Hospital Admissions at the End of Life: A Focus Group Study

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ABSTRACT

PURPOSE Family physicians play a pivotal role in providing end-of-life care and in enabling terminally ill patients to die in familiar surroundings. The purpose of this study was to explore the family physicians' perceptions of their role and the difficulties they have in preventing and guiding hospital admissions at the end of life.

METHODS Five focus groups were held with family physicians (N= 39) in Belgium. Discussions were transcribed verbatim and analyzed using a constant comparative approach.

RESULTS Five key roles in preventing and guiding hospital admissions at the end of life were identified: as a care planner, anticipating future scenarios; as an initiator of decisions in acute situations, mostly in an advisory manner; as a provider of end-of-life care, in which competency and attitude is considered important; as a provider of support, particularly by being available during acute situations; and as a decision maker, taking overall responsibility.

CONCLUSIONS Family physicians face many different and complex roles and difficulties in preventing and guiding hospital admissions at the end of life. Enhancing the family physician's role as a gatekeeper to hospital services, offering the physicians more end-of-life care training, and developing or expanding initiatives to support them could contribute to a lower proportion of hospital admissions at the end of life.

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INTRODUCTION

Despite national end-of-life care policies aiming at home death and most patients preferring not to die in hospital, the acute hospital setting remains a common place of final care and death in most countries.^{1,2} In Belgium, the proportion of hospital deaths has decreased slightly during the last decade, from 55.1% to 51.7% between 1998 and 2007, similar to decreases found in other countries.³⁻⁶ When compared with countries that have lower proportions of hospital deaths, eg, 34% in The Netherlands and New Zealand or 40% in Denmark,^{2,7} and countries that have reported larger decreases in hospital deaths, eg, from 49% to 36% in the United States between 1989 and 2007,⁸ the proportion for Belgium remains persistently high.

Furthermore, despite a decreasing proportion of hospital deaths, the use of hospital services at the very end of life remains high and might even increase. In an elderly population in the United States, intensive care unit use in the last month of life has been shown to have increased from 24.3% to 29.2% between 2000 and 2009.⁹ Moreover, in Belgium, as in other countries, the hospitalization rates of patients who died after a gradual decline have been found to increase exponentially in the last months of life.⁹⁻¹⁴ In-depth research regarding the critical role of the family physician in preventing such hospital admissions at the very end of life is lacking, however.

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Family physicians are thought to play a pivotal role in providing end-of-life care and in enabling terminally ill patients to die at home or in the nursing home where they reside.^{15,16} It has been shown that most people would prefer to be cared for and to die in familiar surroundings,^{17,18} and that these preferences are more likely to be met when the family physician is aware of them.^{17,19,20} Additionally, a nursing home or home death seems to be more likely when the family physician makes more visits in the last 3 months before death,²¹⁻²³ and continuity of care at the end of life by the family physician seems to reduce emergency department use and hospital death.^{24,25} Such continuity is a rare achievement, and being available at all times can be difficult and demanding.²⁶⁻²⁸ Moreover, family physicians might sometimes feel unable to provide up-to-date and adequate end-of-life care,^{26,27,29} and decisions about a transfer to a hospital at the end of life can be complex and multifaceted.³⁰

In Belgium there is a strong emphasis on primary care, with almost 95% of the population having a family physician whom they consult regularly (78% at least once a year).³¹ Moreover, as end-of-life care is integrated into the regular care system, family physicians usually coordinate and provide out-of-hospital end-of-life care.³² They can be supported by specialist palliative care providers, usually at the family physician's request, eg, when the physician does not feel sufficiently competent. Family physicians are therefore considered to be instrumental in preventing inappropriate end-of-life hospital admissions. The family physician's gatekeeper role to hospital services is limited in Belgium,^{33,34} however, because patients or families may autonomously decide to go to a hospital for specific problems without consulting any family physician.³⁴⁻³⁶

The aim of this study was to explore the family physicians' perspectives of how they perceive their own role in preventing and guiding end-of-life hospital admissions and the difficulties they experience within such a role. Unraveling the expectations and tasks family physicians encounter, as well as the difficulties that can arise regarding these end-of-life hospital admissions, might shed some light on the complexity of their role as primary caregiver at the end of their patient's life, as well as any opportunities for improvement in providing adequate end-of-life care.

METHODS

A focus group methodology was considered to be most suitable to comprehend the experiences and opinions of family physicians, given its meaningful process of sharing and comparing.³⁷ We recruited 5 focus groups of family physicians (N = 39) and analyzed verbatim transcriptions using a constant comparative analysis.

Participants

Focus groups participants were members of local peer-review groups. Nearly 97% of all full-time practicing family physicians in Belgium are affiliated with a peer-review group where they discuss aspects related to family practice.³⁸ To maintain accreditation, they are obliged to attend at least 2 of 4 meetings each year. Using pre-existing groups for focus groups has been shown to benefit discussions.³⁹ We contacted by e-mail several groups from different regions across Belgium, and 5 groups were selected according to their availability.

Data Collection

The focus group discussions lasted between 60 and 120 minutes and were moderated and observed by 2 medical sociologists with experience in qualitative research and knowledge of the items needed to be discussed (T.R., D.H.). The data used in this study were collected in the context of a wider study exploring the justifications provided for hospital admissions at the end of life. After completing a short questionnaire and an informed consent form, participants were asked about their experiences and opinions concerning end-of-life hospital admissions in general. Next, a discussion prompted by case descriptions was generated about whether an end-of-life hospital admission would be appropriate or justified—defined as the only or best option for the patient, given the circumstances. During focus group discussions participants were asked to reflect on what they perceived to be their roles as a family physician and what difficulties might arise.

Data Analysis

The focus group discussions were audio-recorded and transcribed verbatim. Analysis was guided by a constant comparative method. After reading and initially coding several transcripts, the 2 medical sociologists developed a coding framework for categorizing the family physicians' roles in preventing and guiding hospital admissions. This initial framework was discussed within the research team (4 medical sociologists, 1 family physician, and 1 nurse). One researcher (T.R.) coded all transcripts and modified the framework where necessary and in consensus with another researcher (D.H.). Results were regularly discussed within the research team, with each team member rereading and recoding several transcripts to ensure consistency and validity. A final thematic framework was agreed upon, and quotes were selected, translated and approved by the research team. Qualitative data were analyzed using QSR NVivo 10.

Ethics approval for this study was given by the Medical Ethics Commission of the Brussels University Hospital.

RESULTS

Characteristics of the participants in the focus groups are displayed in Table 1.

After analysis, we identified 5 key inter-related roles family physicians played in preventing and guiding hospital admissions at the end of life: as a care planner, as an initiator of decisions, as a provider of end-of-life care, as a provider of support, and as a decision maker.

Advance Assessment and Planning Care: A Continuous Process

To be able to prevent hospital admissions during end-of-life care, family physicians take on the role of care planner. Care planning is considered to be a two-way process. First, it is essential that the patient and the patient's family are adequately informed about all options and possibilities associated with end-of-life care. After they clarify their preferences, the family physician can assess the capacity of the care setting and take into account their expectations and preferences.

If the patient eventually reaches a decision, after you have given him all the [information], you are going to respect that wish, I think. It is so, you obviously first have to give a lot of information to that patient, lots of elements which he may not previously have taken into account (Focus Group 1 [FG1]).

Subsequently, care planning is considered to be a continuous process as arrangements and agreements are made throughout the dying phase in an effort to anticipate or forego future hospital admissions.

Participants indicated that it can be difficult to anticipate future scenarios, considering how assessments can change. Moreover, a major problem expressed by participants is that they sometimes feel excluded by hospital specialists and lose sight of patients who are in treatment. As a result, they have to make end-of-life plans at the very end of life, rather than in advance, which hinders their ability to organize adequate care.

I also do think it is a problem, you get them back when they [hospital specialists] themselves do not see where to take it from there, you see. ... And then you have to start making arrangements and discuss the prospects they [the patients] have and, yes, indeed, that is a problem, I agree. And they even may have been hearing something completely different for 6 months or so (FG5).

Initiating Decisions in Acute Situations

Deciding whether to hospitalize in an acute situation involves many different perspectives: the family physician's, the patient's, family members', and caregivers'. Participants indicated that, as a family physician, they

Table 1. Characteristics of Focus Group Participants

Characteristic	FG1	FG2	FG3	FG4	FG5	Total
Participants, No.	7	5	9	13	5	39
Age, average y	53.9	74.6	56.3	55.7	58.4	56.82
Sex						
Male	5	5	8	10	4	32
Female	2		1	3	1	7

FG = focus group.

sometimes need to mediate these perspectives to avoid conflicts, which would otherwise hinder their ability to initiate decisions and to find common ground among those involved.

Moreover, because in the Belgian health care system the family physician's role in deciding whether to admit a patient to hospital is merely advisory, patients' and family caregivers' preferences were generally seen as carrying more weight.

...[S]o you cannot create a conflict. I think you can negotiate, but if he says, "I'm going [to the hospital]," well, then he's going, right. ... And I can [explain] it even further, I am not for it, but that is my opinion, it is his decision (FG3).

Providing End-of-life Care: Competencies and Attitudes

Some study participants indicated that the physician's competence and attitude regarding end-of-life care are important in avoiding hospital admissions at the end of life. Family physicians who were more skilled in end-of-life care were considered to be more effective in keeping the patient at home or in the nursing home. Being able or wanting to keep a patient at home or in the nursing home, however, can also depend highly on the family physician's attitude toward end-of-life care.

I think the avoidability and inappropriateness of hospitalizations at the end of life diminishes depending on your competence of dealing with controlling symptoms. I am sure of that. What is avoidable for one colleague is not necessarily avoidable for another. ...I think it also has to do with the doctor's own attitude. How you think about these things as a person.... If you are convinced that you have to try and save the patient's life in every case and at all cost, with all possible means,... the patient will sooner be admitted to the hospital... (FG1).

Also, being supported by a local palliative care services specialist was considered important and helpful.

Therefore I also found it important to work with a palliative home team for once, to give you some breathing space. ... I think that it also benefits the...family physician's strength when you work with these people (FG4).

Providing Support: Being Available During Acute Situations

Participants believed it was expected that family physicians need to be able to support dying patients at all times and therefore be available continuously, and that being available, where appropriate, can prevent patients from going to hospital. They need to be present in acute situations to support the patients and to convince them and their relatives that the patients can stay at home or in the nursing home.

Some participants, however, also admitted that they cannot always be available as a family physician or they feel more comfortable in admitting a patient to hospital, particularly during weekends.

...[A]nd sometimes we also feel safer when he is in the hospital, you see. That is how it is, that is our responsibility partly given to someone else, on a Friday night, which is also a bit more comfortable, I do admit that (FG1).

Taking Responsibility: Being Able to Make Decisions

Participants explained that family physicians sometimes do need to make decisions themselves about whether to admit a patient to hospital. They believed a family physician should be prepared to make these decisions.

I think that at a certain moment you have to decide for yourself and tell the family clearly: "Look, we can admit the patient to the hospital, he may pull through, but...have you already said your good-byes? Yes or no?" And if they all [say], "Look, we have said our good-byes..." then I think you have to say firmly, "OK, so no admission" (Participant 1, FG4).

But in that case [the family must] unanimously agree in fact and also [suppose]: part wants it and another part does not, it's not simple in that case, and then you have to take your responsibility as a doctor, in a way, I think (Participant 2, FG4).

Some participants indicated that in some situations, for example when they are not sure they can provide adequate care or when they are not sure about the patient's medical situation, they decide to admit a patient to a hospital, particularly when they are on duty after-hours and information is lacking.

DISCUSSION

To our knowledge this study is the first to use a focus group methodology to explore the experiences of family physicians in their roles of preventing and guiding hospital admissions at the very end of life, as well as the difficulties they experience, while focusing on different care settings and disease trajectories. Family physicians in our study indicated that they face many different and

complex roles in dealing with hospital admissions at the end of life and encounter barriers to fulfilling those roles. They need to plan care so they can anticipate future scenarios, initiate decisions in an advisory manner, and try to avoid conflicts. Their own attitudes and expertise in end-of-life care are considered important in enabling patients to remain at home until the end of life. They need to provide support, mostly by being available at all times and particularly in acute situations; and they need to be able to make decisions themselves and to be prepared to take responsibility.

There are several limitations to this study. Despite the advantages of using preexisting groups of family physicians,³⁹ this method might mean that some participants restricted reporting their thoughts or opinions—they might have felt safer not questioning their own or others' competencies in front of their colleagues. Furthermore, although the proportion of male practicing family physicians in this sample is similar to representative national figures, the average age of 57 years was older compared with the national average of 49 years.³⁸ Because there is no clear indication that our recruitment procedure selected for older physicians, and because the short questionnaires completed before discussions showed a great variety of experience and training, we believe the older age has not biased the results, though it should be taken into account. The research team consisted of 4 medical sociologists, 1 family physician, and 1 nurse, all with experience in qualitative research in social health sciences. This multidisciplinary composition of the team provides a good guarantee for adequate reiteration and triangulation of the data interpretation from various perspectives, but they might have guided data interpretation and analysis in the sense that a social health perspective was dominant. Finally, it has to be noted that this study focused on the family physician's role specifically, although such a role is evidently intertwined with other factors.

An important finding in this study is that the Belgian family physicians' limited gatekeeper function might have a considerable effect on their ability to prevent end-of-life hospital admissions, despite their prominent role in enabling patients to die in familiar surroundings. This limited function substantially hinders their ability as care planner and diminishes the weight of their decisions in acute situations. It might also, in part, explain why countries where family physicians are stronger gatekeepers to hospital services, eg, The Netherlands or Denmark, have fewer patients hospitalized in the last 3 months of life^{35,40,41} or have a lower proportion of hospital deaths.^{2,7} It could be suggested, therefore, that adopting a system by which the usual family physician refers patients for most specialized services would be a good starting point to reduce

the number of end-of-life hospital admissions. Family physicians would be included earlier in the end-of-life trajectory, thereby improving their role as care planners and their ability to provide continuity of care,⁴² as well as further strengthen their position as end-of-life care providers.

Another important finding of this study is that the family physician's expertise and attitude toward end-of-life care are shown to be essential in preventing an end-of-life hospital admission. Family physicians appear to differ in their competencies and attitudes toward prevention of hospital admissions at the end of life in that family physicians who do not feel competent are more likely to send a patient to a hospital. Furthermore, feeling incompetent to deal with dying patients might prevent family physicians from taking responsibility for keeping the patient at home or to being available to them. That family physicians are more familiar with cancer end-of-life trajectories^{43,44} might also partially explain why cancer patients are more likely to die at home or less likely to die in hospital, compared with patients dying of other causes.^{3,4,14,45,46} Improving competencies and attitudes through adequate end-of-life care training therefore seems to be essential to reducing the number of end-of-life hospital admissions. Preferably, improved competencies can be accomplished by ensuring basic end-of-life care training is incorporated into family practice curricula. Furthermore, we found that family physicians feel more competent and confident when supported by specialist end-of-life caregivers. Services that support and assist family physicians in providing end-of-life care are important to enable them to keep a patient at home or in the nursing home.

Family physicians face many different roles and difficulties in guiding and preventing hospital admissions at the end of life. Enhancing family physician continuity by assigning them a more restrictive gatekeeper role in access to hospital services and improving their competence and attitudes, preferably by basic end-of-life care training, could prevent more terminally ill patients from dying in a hospital and improve end-of-life care in general.

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Key words: family practice; hospitalization; terminally ill; palliative care; qualitative research; focus groups

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