Dying in hospital: Qualitative study among caregivers of terminally ill patients who are transferred to the emergency department

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Summary

Introduction > Most people in France die in the hospital, even though a majority would like to die at home. These end-of-life hospital admissions sometimes occur in the emergency setting, in the hours preceding death.

Objective > To understand the motives that incite main natural caregivers to transfer terminally ill patients at the end of life to the emergency department.

Methods > A qualitative study was performed among caregivers of terminally ill patients receiving palliative care and living at home, and who died within 72 hours of being admitted to the emergency department of the University Hospital of Besançon, France.

Results > Eight interviews were performed; average duration 48 minutes. The caregivers described the difficult conditions of daily life, characterised by marked anguish about what the future might hold. Although they were aware that the patient was approaching the end of life, the caregivers did not imagine the death at all. The transfer to the emergency department was considered as a logical event, occurring in the continuity of the home care, and was not in any way criticised, even long after death had occurred. Overall, the caregivers had a positive opinion of how the end-of-life accompaniment went.

Discussion > Difficulty in imagining death at home is underpinned by its unpredictable nature, and by the accumulation of suffering and anguish in the caregiver. Hospital admission and medicalisation of death help to channel the caregiver's anguish. In order to improve end-of-life accompaniment, it is mandatory to make home management more reassuring for the patient and their family.
Introduction

In France, more than half of all deaths occur in hospital. In 2012, 57.1% of all deaths occurred in hospital, compared to 24.8% who died at home [1]. These statistics have been stable for the last 20 years, even though the majority of healthy individuals express a desire to die at home [2]. The situation is similar in most European countries, where France ranks mid-range in the number of in-hospital deaths [3].

Yet, as death becomes imminent, the rate of hospital admissions rises among home-dwelling patients at the end of life [4]. Most of these patients are admitted to the emergency department (ED), where they sometimes die on the day of admission. Among the 14,000 patients who died in EDs in France in 2010, around 30% were in the terminal stages of palliative care [5]. Intuitively, EDs do not appear to be the most suitable place for end-of-life accompaniment of dying patients. Firstly, the ED is generally designed for initial technical management, rather than focussing on relations with the patient, and secondly, the mission of the ED is to manage as a priority life-threatening or functional-threatening medical needs, rather than accompany the end of life [6,7].

What is already known

- The rate of deaths occurring at home is low, despite the fact that many people wish to die at home.
- Emergency departments experience a large number of emergency admissions of terminally ill patients who are at the end of life.

What this study adds

- The accumulation of difficulties at home, and the lack of preparation of the caregiver in accompanying the end of life lead to the rupture of the home-care model, and prompt the caregiver to transfer the patient to the emergency department.
- Hospitalisation of a dying patient at the last minute can be a positive experience for the caregiver (who has the feeling of having kept the patient at home as long as possible).
- It is mandatory for end-of-life accompaniment to focus more on the caregiver, particularly with more information about what may happen at home.
Except few studies [8,9], qualitative research pertaining to emergency hospital admissions in patients with terminal illness is sparse [10]. Especially the perspective of the caregivers and the time at which the transfer to the hospital setting occurs are poorly documented. What are “ED for dying”, the emergency admission of patients who had chosen to die at home, only to die soon after admission to the ED? How to understand this place of death which seem not rational?

The objective of our study was to understand the motivations of primary family caregivers (PFC) in transferring a patient with terminal illness to the ED. In particular, we sought to understand the role and influence of non-medical factors contributing to the decision to transfer the patient to the ED, especially emotions and the caregiver’s own difficulties in accompanying their loved one.

**Methods**

**Study design**

We performed a qualitative study by means of semi-directed interviews with PFCs of patients with terminal illness who were living at home, and who died within 72 hours after being admitted to the ED of the University Hospital of Besançon, France.

**Recruitment**

We included all PFCs of patients in the palliative phase of terminal illness who were living at home, and were admitted to the ED of the University Hospital of Besançon, France. Patients were included between 15 February and 15 May 2015. All included patients had expressed the desire to die at home, or in the absence a specific desire to die at home, had not expressed a specific desire to die in the hospital.

Primary family caregiver (PFC) was defined as a non-professional caregiver (family member or not) who accompanied the patient in their home at the end of life. The palliative phase of terminal illness was defined as the presence of all the following criteria:

- death related to a chronic serious disease;
- death within 72 hours following admission to the ED;
- therapeutic objective limited to comfort care only for the patient, or a decision not to escalate therapy.

The time frame of 72 hours was chosen according to the definition of the Société française d’accompagnement et de soins palliatifs (SFAP, French Society for Accompaniment and Palliative Care) of the terminal phase [11], and based on a prior pilot study [12] (the time frame being judged as the shortest possible time that would allow a sufficient number of eligible patients to perform 10 interviews during the inclusion period). According to the SFAP definition, the terminal phase is characterised by failure of the major vital functions (cardiovascular, respiratory, and/or neurological), resulting in absence of resuscitation at death.

We excluded PFCs who were aged < 18 years (since we considered that the issues relating to underage PFCs would be different to the problem under investigation in this study), and PFCs who lacked the physical or psychological ability to participate in the interview.

We verified the inclusion criteria of the patient and PFC by checking the patient’s medical file, and by telephone contact with the patient’s general practitioner (GP). PFCs were informed of the study objectives and procedures by post, and were subsequently contacted by telephone to obtain consent to participate. All participants signed a non-opposition form before the interview, in accordance with French legislation.

The Clinical Ethics Committee of the University Hospital of Besançon approved the study (date 18/02/2015). Approval was also obtained from the French National authority for the protection of privacy and personal data (CNIL) under the number 1830225v0.

**Data collection**

Face-to-face semi-directed interviews were performed with the caregivers 6 to 12 weeks after the patient’s death. This time-frame was defined after consulting with a psychologist from the palliative care unit of the University Hospital of Besançon, since a shorter time between the death and interview was judged to be unsuitable, in view of the intensity of the emotions experienced after the death. Conversely, a longer time delay would induce a risk of memory bias, and would coincide with a more difficult stage of the grief process [13].

The interview guide was prepared by the primary author (a resident in family medicine, specialising in palliative care, with training in qualitative research), the MD PhD leading palliative care unit and research unit, and a clinical psychologist in palliative care unit, based on data from the literature [12]. The interview guide was tested during the first three interviews, but required no further changes for the subsequent interviews. The interview guide aimed to explore three main themes:

- the experience and representations of the caregiver regarding the accompaniment of the patient in the home setting, particularly perceptions about the end of life;
- the representations regarding transfer to the ED, particularly the specific factors that contributed to the decision to transfer, and what they expected from the hospitalisation;
- the emotions and reactions of the caregiver after the death of their loved one.

All interviews were performed by the primary author. After informing the subjects and obtaining their consent, the interviews were recorded using a digital microphone and transcribed in their entirety using Microsoft notepad.

**Analysis**

Data were coded using RQDA software. RQDA is a free qualitative analysis software for analysis of textual data. It can be used for manual coding of texts and categorization of codes (http://...
The experience and representations of the PFC at home

Difficulties in daily life

This theme was predominant in the caregivers’ discourse. During the interviews, the caregiver focused on the difficulties related to the daily life of their sick loved one. All the caregivers described the magnitude of the task of caring for their loved ones, often turning their own life upside-down. The role as caregiver required that they give up their own needs, and it exposed them to physical and psychological exhaustion.

I was finding it harder and harder. I was very tired too because it's really hard. I was minding my Dad, my Mum and the whole house... It was hard all the same. I was exhausted, very tired... And transferring him to get him to sit on his chair, because he would only let me do it. It was really hard for me, I was worn out from it all. Even my morale wasn’t good. I’d go home in the evening, and I’d be upset... I'd be thinking, The poor thing, what a state he’s in... I’d be going back over it in my mind, you know? [1].

The accompaniment transformed the roles and bearings within the family, and the caregivers often had to take on the role of healthcare provider. The caregivers accepted this responsibility and the situation could represent a new type of relationship with their loved one.

In any case, she couldn't have lived alone after that. Because she needed the walking frame all the time, I followed her everywhere, even when she was going to the toilet... At the end, it was hard, it was very tiring, it was... But I did because it was only normal, because it was my mother... [2].

For the caregiver, daily life at home was characterised by a permanent and major stress, focused on the perspectives for home-based hospice care, and particularly, a fear that things would get worse, although the word death was never mentioned.

At night I would look at her, when she was lying down, and I think, what’s going to happen to us? And you're always afraid of when that time comes [2].

This apprehension was associated with a feeling of isolation among the caregivers, irrespective of the level of support from family and professionals in the home.

Personally, I struggled alone at night with my husband, and it wasn’t easy! [6].

The home as a place of psychological safety

The home setting appears as an ideal place, despite the suffering and anguish of the caregiver. The home is where life follows its normal course, in the continuity of the patient's personal and family history.

But apart from that, it was mainly one-day stays at the hospital and when we’d get home, he would say “Phew, we’re home at last!” He had his little foibles, for example he had this chair, and he’d put it on the patio, and that was his spot. Sometimes when the kids would come over, they'd poke fun at him, saying "Look at you, L., your chair and your tomato juice and your celery salt" [caregiver laughs]. you know, he was happy at home with us [8].

Home-help professionals, especially nurses, play an important role because of the reassurance they provide and through the

www.rqda.r-forge.r-project.org/). The verbatim were coded into descriptive themes, then further categorised into analytic concepts. A first level of descriptive coding was performed, followed by the emergence of a progressive interpretation of the data through constant comparison of the different situations. The successive stages of coding and interpretation were discussed in an interdisciplinary setting (primary author, sociologist, philosopher, and medicine from the research team) based on the principles of grounded theory [14,15].

Results

Sample characteristics

From 15 February to 15 May 2015, 21 patients in the palliative stage of terminal illness and admitted from their home, died within 72 hours of their admission to the ED of the University Hospital of Besançon. Four patients had no known PFC. Among the 17 remaining patients, 11 PFCs could be contacted and eight accepted to participate in the interview.

The reasons cited by the three PFCs who refused were that it was too soon after the death, or they did not want to talk about the situation.

Among the 8 participants in the interviews, there were 7 women and 1 man; half were the spouse of the deceased patient, and the other half were children of the deceased. The median age of the patients at the time of death was 85 years (range, 69 to 91). Four of the patients had cancer, three had neurodegenerative disease (Alzheimer’s disease, Parkinson’s disease or amyotrophic lateral sclerosis), and one had chronic renal failure.

The average duration of the interviews was 48 minutes. Seven took place in the PFC’s home (of which 5 were in the place where the patient had spent their end of life prior to transfer to the ED), and one took place in the University Hospital of Besançon. All interviews occurs between 46 and 82 days after patient’s death (average 66 days).

Among 21 patients of the sample, 11 left the hospital in the three weeks preceding their readmission. Five of them left the hospital within one week before there readmission.

Findings
Despite a clear "open awareness" of dying [16], the terminal phase and death were absent from the representations and images portrayed by the caregivers. Death, even a tranquil, peaceful one, was simply not envisaged, and the caregivers were never prepared for it.

M: How did you imagine she would pass away? At home? or in the hospital?
I: Ah no, not that. Neither at home, nor in the hospital. I knew she was very sick, I knew about all she had, but I was always looking ahead, I’d say “now’s not the time, it’ll never happen”. You never expect it to happen. You know things aren’t going well, but you just think, no, never—at least for me, never, no. It won’t happen right away, you always know it’ll be yes, but just not now [4].
I didn’t imagine it at all, I was hiding my head in the sand. Because the nurse said to me, “you know, N., you need to prepare yourself. Your father, he’s not going to… You’ll have to deal with that, maybe see a psychologist, or someone”. But I didn’t want to know, I couldn’t face the facts [1].

The caregivers also failed to imagine and prepare for the place of death. There seemed to exist a split between their representations regarding the end of life and regarding the place of death.

M: Did you not imagine that he could die at home?
I: I don’t know, I hadn’t thought about it.
M: Either way, it didn’t make you afraid?
I: No. The thought never crossed my mind [3].

The discourse of the caregivers often juxtaposed the conditions at home with the conditions in the hospital. Although seen as a reassuring environment, the hospital was nonetheless described as a hostile and unsettling place for the patient. The caregivers reproached the hospital with a failure to take psychological support into account, both for the patient and for the caregivers themselves.

When she went to the hospital, my mother was completely lost. When she was… she wasn’t all there but when she stayed in bed for 10 days… when she wasn’t in her own environment, I knew that she wasn’t herself in the hospital because she didn’t have her usual surroundings and all that. But when she got home, she had her usual surroundings, and she was perfectly alright [4].

The caregivers particularly emphasized several points about the hospital, such as getting contradictory information, the cold manner of announcing a diagnosis, the lack of consideration for the patient, and the failure to recognize the patient’s special status as a person in an end-of-life situation. The caregivers found these problems to be particularly marked in the emergency department, which was often described as being unsuitable for end-of-life patients.

They’re overworked, I’ll grant you that. But they still have to realize that they’re working with human beings. That’s all I ask for, nothing else [6].
But I went to the hospital all the same, I know what it’s like, you’re not exactly considered as an object because they’re attentive and that, but you know… The nurses and the doctors, they haven’t the time to sit around talking about our troubles [8].

The topic of the transfer to the hospital represented only a small part of the caregivers discourse and it was not experienced as a key moment of the accompaniment. It was not seen to result from a deliberate choice, but rather just the continuity of a logical process in light of the perceived deterioration of the patient’s medical status. In a few cases, a third party, rather than the caregiver, made the decision to transfer the patient to the hospital.

Ah no, I would’ve preferred, I would’ve preferred, but what can you do. The doctor, the doctor was categorical about it, he said “you can’t keep her there”. [Silence] I took his word for it [5].

The reasons for transferring to the hospital were more the fear that an acute symptom might appear that the caregiver thought...
might be unmanageable at home, rather than the actual existence of any such symptoms.

Well... if we had left her at home, we would've been worried, thinking, "you see, she's going to... maybe she'll be suffering", we didn't know if she was suffering at that time. It's difficult, isn't it? [7].

The caregivers were quite vague about what they actually expected from the transfer. Most seemed to have a two-fold expectation: firstly, relief of symptoms to ensure the patient's comfort, and secondly, active treatment of the complication to prolong the patient's life.

Well, you know, you always think well, at the hospital, they're there to save people's lives, you see what I mean, even if it's an old person who's at the end of life, who's... you think, well, if we keep her at home, maybe we'd always be thinking "oh dear, we should've taken her to the hospital all the same, maybe they could've saved her for another few months" [7].

Emotions and reactions after the death of the patient
Overall, after the death, the caregivers still had a very positive attitude towards the accompaniment at home, and particularly towards the transfer to the hospital. None of them called into question the legitimacy of the transfer, and no caregiver said that they regretted not having accompanied the person to the end at home. On the contrary, the caregivers expressed significant relief at the fact that the death occurred in the hospital. Rather than seeing the move to the hospital as a failure of the care, they expressed satisfaction with the hospital stay. In contrast with expectations, they were "the unthinkable". The caregivers were unable to anticipate psychologically, despite being clearly aware of the end-of-life nature of the situation.

Surprisingly, the topic of the transfer to hospital did not occupy a large part of the caregivers' discourse. Indeed, probably because it occurred at the pinnacle of the anguish and worry felt by the caregivers in the face of signs of imminent death, the transfer to hospital was seen as a sort of relief, a form of help at a very difficult and lonesome time.

The suffering and anguish of the caregiver as contributing factors in the decision not to keep the patient at home any longer
The decision to admit the patient to the hospital did not appear to be a response to an acute, isolate medical episode [17], but rather the ultimate consequence of a build-up of exhaustion, suffering and worry during the time they accompany the sick person at home. When the decision was made to hospitalise, it was not a choice that they consciously make, but rather the only remaining reaction possible in the face of their own distress. This distress can be generated by numerous factors that compound caregiver suffering, such as the disruption of their home life by the constant presence of professional personnel, the rhythm imposed by the necessity for regular care, caregiver exhaustion, awareness of the decline of their loved one, and the transformation of the relationships and roles within the family. All these elements were identified in this study, and have been previously reported in the literature [18,19].

In parallel, the increasing anguish felt by the caregiver in the course of the accompaniment appears to be omnipresent in the home setting. It seems to be the reflection of the unimaginable perspective of the patient's death, which is paradoxical given that the caregivers are aware that the patient is deteriorating and that the end of life is imminent [20].

This lack of preparation by the caregivers for the death of their loved one portends difficulty with the future bereavement, and raises the question of the role of professional healthcare providers in helping carers to prepare themselves. It is also clear that this anguish is not only related to the symptoms, and seems to be wholly related to death itself, even when the person passes away peacefully.

At the height of their anguish, the carer's only response was to fall back on the doctor and the hospital. The physician, who usually is not involved in the day-to-day accompaniment, resumes a central role as death becomes imminent, while the involvement of other healthcare professionals, previously foremost in the accompaniment process, wanes. However, if the physician is also unprepared for this experience [21], their response can be stereotypical and ill adapted, i.e. hospitalisation and "medicalisation" of dying. Certain authors have shown that responding with simple presence, rather than initiating medicalisation, can allow adequate accompaniment at the end of life, even in the home [22].

The place of the dying at home and in the hospital
Before the final transfer to the hospital, home is seen as the natural place to live out the end of life, because it represents the continuity of the patient's personal and family history. Non-physician healthcare professionals, especially home nurses, are considered by the patient's family to have a central role in helping carers to prepare themselves.
role, not only because of their technical skills, but also thanks to the close relationships they build with the patient and the family over time. This bond that is created between professionals who come to the patient’s home is quite the reverse of what the family experiences when the patient is admitted to hospital. Conversely, the general practitioner was not generally considered to be a key player in the home-care setting in our study, contrary to previous reports [2].

The time when the decision is made not to keep the patient at home any longer represents a complete turnaround of the acceptability of each place: the hospital – previously considered as a hostile environment – becomes a haven of safety, while in parallel, the home becomes unacceptable. This reversal may reflect the unacceptable nature of dying at home, while it is a safe place to live where death can be denied [23]. This finding mirrors the Ariès’ concept of “forbidden death” [24], and the need to push death outside the home and outside the social sphere.

Strong points and limitations of the study

This study addresses an original topic that has heretofore been explored exclusively through quantitative research methods. The decision to use a qualitative approach made it possible to access new perspectives in the question of terminally ill patients attending the emergency department, and the role of natural caregivers in this process.

The inclusion criteria chosen for this study made it possible to explore a wide variety of situations, without limiting the population to oncology patients. The fact that we found a similar incidence of terminally ill patients attending the emergency department as in previous reports from France [5,25] suggest that our inclusion criteria have good external validity. However, the failure to achieve saturation (due to the exploratory nature of this study) call for continued research in this context in the future, with a larger study population.

This is a single-centre study conducted in the context of the French healthcare system. Practices may be different in other healthcare systems, and thus, multi-centre studies at an international level are warranted to verify the generalisability of our findings.

Lastly, in parallel to this study of natural caregivers, it would also be useful to investigate the same topics among the first-line medical professionals (especially the generally practitioner and home nurses), in order to describe and understand their role in decisions to hospitalise end-of-life patients.

Conclusion

Our study showed that there is a clear separation between the home, considered as a place of life and experience, and the hospital, considered as a place where care is dispensed. It seems to underline how unthinkable it is that death should occur in the home, because the caregivers never imagine that this can or will happen.

On the other hand, our study also showed that the medical environment, epitomised by the hospital, was deeply implicated in a sort of false hope conveyed by the medicalisation of dying. The medical environment seems to represent a vent for the family to release pent-up feelings of anguish.

Lastly, the anguish generated by the unthinkable death of a loved one can only be relieved by the initiation of an open and honest dialogue between the patient, the family and the physician, regarding a medical plan for end-of-life accompaniment. Anticipating the inevitable complications that the future holds will make it possible, at the very least, to limit the unexpectedness of the events. The new model of advance directives, currently being promoted and communicated in the framework of a new plan for the development of palliative care [27], could represent one useful tool towards initiation of such open dialogue.

Perspectives

It seems essential to re-orient the focus of end-of-life accompaniment to the home, and the patient’s natural environment. To achieve this, a conscious effort to de-medicalise the end of life must be undertaken and pursued. The home setting will only become a safe place to live out the end of one’s life when it is considered as such not only by the patients and their families, but also by home healthcare professionals and hospital-based healthcare providers. In this regard, the focus on outpatient and home care [“virage ambulatoire”] of the recent French legislation on healthcare provision is line with this objective [28]. That need to re-center medical means on home care and better supporting general practitioner. This goal could be reach by developing two major axes. On the one hand by a logistic support by territorial support platform [plate-forme territorial d’appui]. And on the other hand by bringing some palliative medicine competence to the general practitioners, for example in opening mobile palliative care team [équipe mobile de soins palliatifs] activity to them.

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