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

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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 even 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.

Résumé

Mourir à l'hôpital : étude qualitative auprès des aidants de patients en fin de vie transférés aux urgences

Introduction > La plupart des français décèdent à l'hôpital alors que la plupart d'entre eux souhaitent finir leur vie à domicile. Ces hospitalisations ont parfois lieu en urgence, dans les heures précédant la mort.

Objectif > Comprendre les motivations des aidants naturels principaux dans le transfert aux urgences d'un patient en situation palliative terminale.

Méthode > Une étude qualitative a été réalisée auprès des aidants de patients en situation palliative terminale vivant à domicile et décédés dans les 72 heures qui ont suivi une admission aux urgences du CHRU de Besançon.

Résultats > Huit entretiens ont été réalisés, d’une durée moyenne de 48 minutes. Les aidants décrivaient un quotidien difficile, marqué par une forte angoisse de l’avenir. Bien que la conscience de la fin de vie de leur proche était claire, la mort n’était pas imaginée. Le transfert aux urgences apparaissait comme un événement logique dans la continuité de la prise en charge à domicile. Il n’était pas critiqué, y compris à distance du décès. Les aidants portaient un regard favorable sur le déroulement global de l’accompagnement.

Discussion > La difficulté à imaginer le décès à domicile est sous-tendue par son caractère imprévu et par l’accumulation de la souffrance et de l’angoisse de l’aidant. L’hospitalisation et la médicalisation de la mort canalisent en partie cette angoisse. L’amélioration de l’accompagnement de fin de vie nécessite de rendre plus sécurisante la prise en charge à domicile pour le patient et ses proches.
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