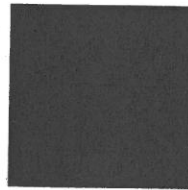


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Return home at the end of life: Patients' vulnerability and risk factors

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Abstract

Although most of the people in good health questioned about the subject said they would like to die at home, in the western world between 60 and 80% of deaths occur in hospital. Most authors consider that the indispensable conditions for a return home are the patient's desire and presence of the family and caregivers with the appropriate skills. The assessment of other factors predictive of a return home is inadequate. The aim of this study is to clarify how the return home is influenced by the vulnerability of the patient at the end of life, and by that of the family and caregivers. We carried out a multicentric, observational, prospective, exhaustive and longitudinal epidemiological study (three months follow-up), including 146 patients hospitalized at the end of their life and desiring to return home. For these patients the caregivers respected their freedom to choose to die at home in over half the cases (56%). Their overall vulnerability (personal, family context and caregivers) had a significant influence on the return home. This overall vulnerability was in fact identified as applying in 40% of the clinical situations, and made the possibility of a return home 50% less likely.

Keywords

Autonomy, end-of-life care, palliative care, vulnerability

Introduction

In the vast majority of cases (between 60 and 90%), people die in hospital.^{1,2} However, when people in good health are asked what they want, between 60 and 80% declare they would prefer to die at home.^{1–4} The same is true for hospital patients towards the end of their life who express the desire to return home. Some of them will receive a positive response to their request, others will not. What does this mean? Do the caregivers take no notice of the patient's freedom to choose? Are some patients close to death too vulnerable to return home? Are the means for organizing palliative care on an outpatient basis still too inadequate to allow these patients to be managed outside the hospital?

Most authors consider that the indispensable conditions for a return home are on the one hand the

patient's desire, and on the other the presence of family and caregivers with the appropriate skills. The other factors predictive of a return home, such as sex,^{5–10} age,^{5–9,11–14} urban environment,^{14–16} use of home hospitalization (HH) services^{17,18} and evolution of the illness,¹⁵ are not well assessed and the results are often contradictory.

Apart from the socio-demographic factors mentioned above, to our knowledge there has been no prospective study of the influence of the end-of-life patient's vulnerability from the clinical, ethical and practical points of view with respect to the return home, nor of that of the family and caregivers.

The aim of this study is to clarify the influence of this overall vulnerability (patient, family, caregivers) on the return home.

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Methodology

Study structure

We carried out a multicentric (four hospital centres: one university hospital (tertiary teaching hospital), one cancer institute (reference centre), two general hospitals in the Saint-Etienne area) observational, prospective, exhaustive and longitudinal (three months of follow-up) epidemiological study, including all consecutive cases of end-of-life patients between February 2007 and March 2008.

The study received the approval of the Saint-Etienne ethics committee, Institutional Review Board (IRB) 00005951, on 19 January 2006.

Patients

Patients hospitalized in medical departments were included. These were sick adults (age ≥ 18), at the end of life (Karnofsky index $\leq 40\%$), for whom palliative care was appropriate (defined by the French society for palliative care¹⁹ as suffering from a serious, ongoing disease compromising the vital prognosis, in the advanced or terminal phase), who wanted to return home, and having given oral consent for follow-up on an observational basis.

Assessment tools

The vulnerability factors were studied using the 'Support Team Assessment Schedule (STAS)', the only schedule validated in French.^{20,21} The caregivers filled out the vulnerability factors assessment schedule.

Vulnerability is the sum of physical, psychological, social and spiritual weakness and is based on specific items related to each symptom.

Eleven items of varying nature concerned the patient: physical (pain, symptoms of discomfort), psychological (anxiety, personal feelings: guilt, lack of confidence), ethical (patient's awareness of their life expectancy, communication between the patient and their family and between professionals and the patient) and practical (personal project satisfied, practical help at home, financial problems, wasted time). Two items (anxiety and awareness of the patient's life expectancy) concerned the family; while three (proper communication between professionals, impact of professional staff's anxiety and other professionals' opinions) concerned the caregivers. Each item was scored 0 (symptom under control) to 4 (symptom not under control) and 9 (unknown answer). The overall score obtained defined the patient's overall vulnerability, by which is meant all the vulnerability factors concerning the patient, their family and caregivers, with a potential range from 0 to 144. This allowed us to define two categories based on balanced populations (median): no vulnerability, proven vulnerability.

Study structure

On D0, D30, D60 and D90 (Figure 1), it was noted if the patient was alive or deceased and if they had made use of a specialized palliative care structure (mobile palliative care and support team, town-hospital network, HH services).

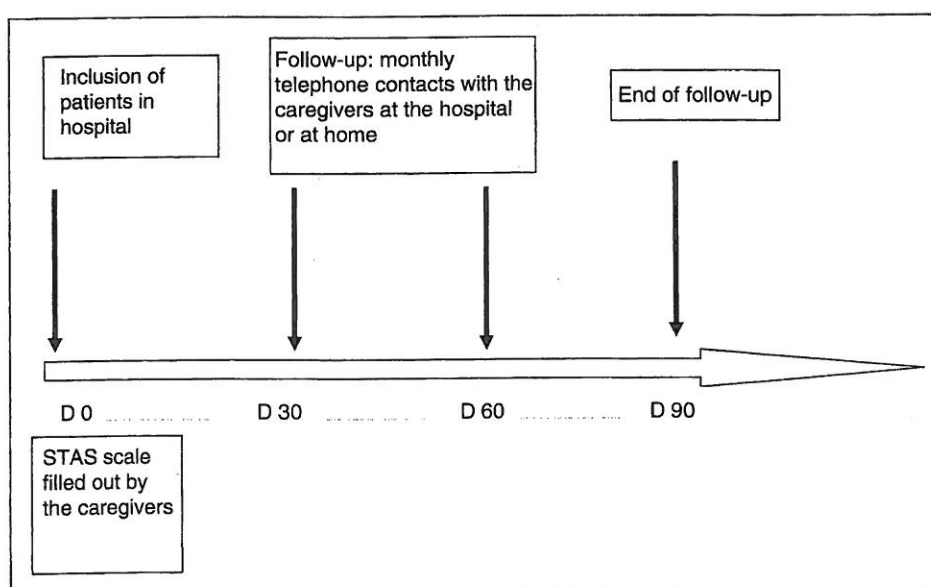


Figure 1. Diagram summarizing the structure of the study.

Communication between the patient and their family was described as 'frank' for 77% of cases, whereas Chvetzoff et al.³⁴ considered it to be so in only 30% of cases. Towers³⁶ concluded that the main problem lies in difficulties with communication, a situation that we did not find in our study.

Factors of a practical nature contribute to the social vulnerability of the person at the end of life and have an impact on the return home.

Putting their affairs in order did not pose any problem for 69% of patients who did so before dying or had already organized everything, or in fact did not want to do anything.

The organization of practical assistance is associated in a significant fashion with a return home. Indeed, 67% of patients who received such assistance returned home, compared with 43% who did not ($p=0.005$). This result concurs with that of Gomes and Higginson,¹⁵ who quoted organization of the home and care among the six factors most often associated with a return home.

When considering the material aspects of the end of life, the financial aspect must not be overlooked. In our study, the problem of financial resources had no effect on the return home. The mean age (71) and conditions for management at home offered by the French health system may explain the lack of any influence of financial resources. This financial assessment is an integral part of management of end-of-life patients, in accordance with the recommendations of several scientific societies in connection with the end-of-life and palliative care, notably the European Association for Palliative Care (EAPC).³⁷

We were able to show that during the three-month patients' follow-up, the use of a structure specialized in palliative care was highly significantly ($p < 0.001$) associated with a return at home. Many authors^{3,12,16,34,38,39} observed the same findings. It would be a mistake to conclude that this return home is solely connected with access to these kinds of specialized structure, as shown by Gomes and Higginson.¹⁵ In fact, all the patients had access to these kinds of structures, but not all of them used them. Why? Among other obstacles were noted reticence of clinical departments, lack of preparation for a return home and unawareness of the existence of other resources within the hospital itself and externally.

We can conclude, like Wright et al.,⁴⁰ that it is absolutely essential to take the social context into account when considering a return home for end-of-life patients.

In addition to the patient's vulnerability, we wanted to take the family's vulnerability into account. Hence the importance, for Kovacs et al.,⁴¹ of giving the family back its place during the end-of-life period. In our study, the caregivers reported that in the great majority

of cases (87%), the families were aware of the seriousness of the prognosis, while the proportion dropped to 52% for Chvetzoff et al.³⁴ Nevertheless, the family goes through various crises. In our study one third of the families presented anxiety. The findings in three studies, carried out by Grunfeld et al.,⁴² McLean and Jones⁴³ and Kurtz et al.,⁴⁴ were in agreement concerning this aspect of the question. This psychological suffering may sometimes take the form of a flight from reality expressed by the refusal to take charge of the patient at home. This refusal is caused by the fear of coming face-to-face with death. This phenomenon may explain one of the results of our study: when the main helper is not a close family member it is easier for the patient to return home.

Consideration of the absolute vulnerability of a hospitalized patient implies that the vulnerability of the caregivers must also be considered. In our study the caregivers declared no communication problems nor feeling that they conveyed any anxiety to the patient, nor any need to consult other health professionals for their opinion, these being the three factors that measure the vulnerability of caregivers. This absence of any anxiety on behalf of the professionals and the patients' return home are closely correlated ($p=0.008$). The fact that the caregivers did not feel the need to call on the skills of other professionals is also clearly correlated with the decision for a return home ($p=0.09$). It should nevertheless be mentioned – and for us this is an important explanatory factor – that a structure specialized in palliative care was called for in for 114 patients (i.e. 79%).

When carrying out this study, the main difficulty encountered was identifying which patients wanted to return home. Many doctors told us only about those patients for whom a return home was already being considered, involving a palliative care network or a HH structure.

We chose to ask the caregivers to fill out the vulnerability factor assessment scale, so it is possible that the caregivers' assessment does not match what the patients felt. Why did we choose to operate in this way? We felt it was inappropriate and even (maybe mistakenly) unethical to meet patients at the end of their life whom we did not know and whom we would not see again, to ask them highly personal questions and others about their experience with their illness. So we preferred to contact the caregivers who were in charge of these patients and whom the patients knew.

Finally, this study shows that the caregivers seem to respect the freedom of choice of patients at the end of their lives, as shown by the high proportion (56%) of patients who did return home. So, in spite of being vulnerable and in an uncertain situation, the patient remains independent in their ability to decide whether

to return home. However, they are not free to decide when it is a question of their own vulnerability (this overall vulnerability increases the impossibility of returning home by 50%), or their dependence on others (patients return home more often when the main helper is not a close family member), or their need for a supportive environment, notably structures specialized in palliative care whose involvement acts in favour of a greater number of patients returning home.

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Competing interests

The authors declare that they have no competing interests.

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