Number 524
June 2015

Population & Societies

A majority of people would prefer to die at home, but few actually do so

Version française

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Most people would prefer to die in their own bed, but only a quarter of deaths occur in the home. Using data from the "Fin de vie en France" [End of life in France] survey, Sophie Pennec and colleagues describe the places where people live in the month preceding their death. They examine transfers between the home, care institutions and hospitals to understand why so few people remain at home during the last weeks of their life.

Up to the 1950s, in France as in other western countries, most people died at home. Since then, however, home deaths have become increasingly infrequent, and they now represent just 26% of the total. [1] The proportion is similar in the United States (24%), but even smaller in the United Kingdom (20%) and Norway (18%).[2] Yet in France, as elsewhere, when individuals are asked where they would prefer to die, the home is generally their first choice. [3] [4] The "Fin de vie en France" survey (Box 1) describes the residential trajectories of persons aged 18 and over during their last month of life. It reveals how difficult it is for dying people to stay in their own home, and sheds lights on the reasons why they so often end up in hospital. The place of death is often determined by the place of residence in the last weeks or days of life. The survey data can be used to examine how people who spend their last month in their habitual living environment differ from those who are hospitalized, and how their care is managed.

Home care becomes less frequent as death approaches

One death in five occurs suddenly, and in half of such cases, it takes place at home. As such deaths are

Box 1. The "Fin de vie en France" survey

The "Fin de vie en France" survey conducted by INED was a retrospective study that involved questioning physicians on the circumstances in which patients died (home, hospital care home). The survey sample consisted of decedents for whom the medical circumstances of the death and some personal and family characteristics were established from a self-administered questionnaire filled in by the physicians who had signed their death certificates. [5] The initial sample of 14,999 decedents aged 18 and over was representative of the 47,872 deaths that had occurred in France in December 2009. The anonymity of responses was guaranteed by the use of trusted third parties who ensured that all data was anonymized before analysis. The overall participation rate was 40%. This is around the average for national surveys of physicians in France. [6]
The survey provides data on the decedents' place of residence on four different dates: 28 days, 7 days and 1 day before death, and on the day of death. All four dates were known in 84% of cases. The closer the date to the time of death, the more frequently the physician knew the place of residence.

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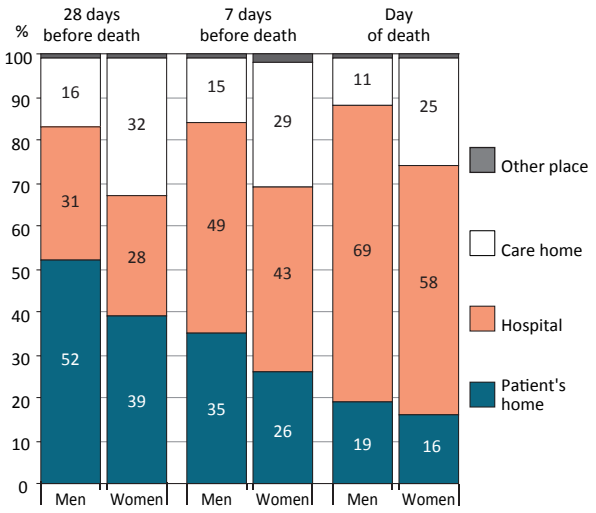
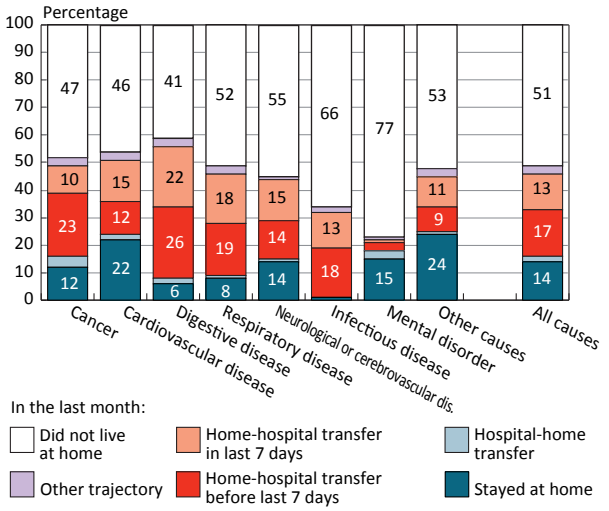
Figure 1. Place of residence at different dates preceding death, by sex



S. Pennec, *et al. Population & Societies* n° 524, INED, July-August 2015.

Source: "Fin de vie en France" survey, INED – 2010.
Coverage: non-sudden deaths of persons aged 18 and over.

Figure 2. Trajectories of persons who spent all or part of their last month of life at home, by cause of death



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unpredictable, no specific form of care is provided beforehand. Conversely, four in five deaths are not sudden; they are the endpoint of a residential and medical trajectory that is recorded in the survey. These are the deaths that will be examined in this article. Four weeks before death, living at home is the most frequent situation (52% of men and 39% of women, i.e. 45% for both sexes combined); 24% live in a care home and 29% are already in hospital. As the partner is the primary carer in cases of dependence, living with a partner more frequently enables men to stay at home than women; twice as many women as men are in a care home (32% versus 16%) (Figure 1). The proportion already in hospital is the same for both sexes (around 30%). As death approaches, hospitalization becomes more frequent and the proportion still living at home decreases. Over the last month of life, the proportion in hospital more than doubles – almost seven in ten men and six in ten women die in hospital – while the proportion who stay at home follows the opposite pattern: only a small fraction of men and women (19% and 16%, respectively), die at home. The place of residence 28 days before death differs by age. The youngest are more often at home: almost 60% of persons aged below 70 versus 30% of those aged 90 and above, who are more often living in a care home. The probability of dying at home varies little with age, however (15-20% are at home on the day of their death).

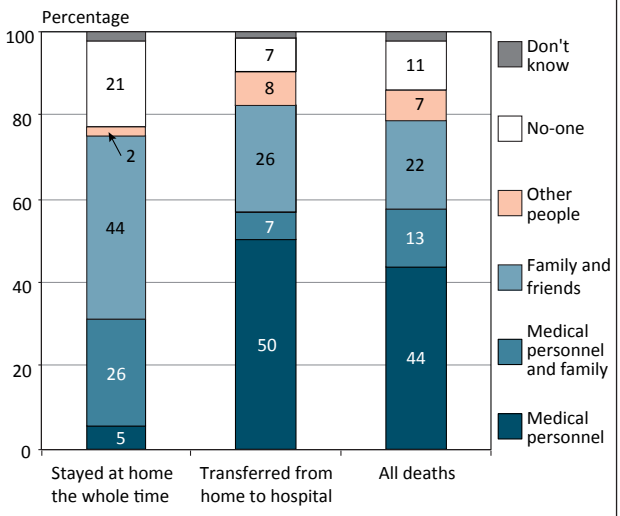
(1) After adjustment for the different survey variables, notably of a medical nature, age and sex do not affect the probability of being transferred from home to hospital.

In cases of non-sudden death, there is a large variety of residential trajectories between the place where a person dies and the place where he or she was living a few weeks earlier. The most frequent pattern is a move from home to hospital before death (30%); just 14% remain at home throughout the last month of life (Figure 2). A move back home from hospital is much rarer (2%), as are complex trajectories between the two (3%).[1]

Certain medical conditions are incompatible with home care

At this late stage of life, a person's place of residence is partly linked to his or her illness. [5] Persons who die of mental disorders or infectious diseases are cared for at home much less frequently than the others (Figure 2). Those who die from infectious, respiratory or digestive diseases rarely stay at home throughout their last month (1%, 8% and 6%, respectively); they are generally taken to hospital at some point. For persons who die from a cardiovascular disease, on the other hand, staying at home until death is almost as frequent as going to hospital (22% and 27%, respectively). Whatever the cause of death, the frequency of hospitalization increases as death approaches: as many people are hospitalized in the week preceding death as in the three previous weeks in cases of cardiovascular disease (15% and 12%, respectively), neurological diseases (15% and 14%) and respiratory diseases (18% and 19%). This finding may reflect a hope that the patient's condition will be improved or cured in hospital, but also signals the difficulties encountered by carers, family members especially, in coping with the final

Figure 3. Distribution of deaths by persons present at the time of death and end-of-life trajectory



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stages of a fatal illness. These situations are more often treated as emergencies, with hospitalization being seen as the only "solution" for managing unanticipated complications. Indeed, compared with persons who remain at home, those who are hospitalized the day before death twice as frequently (56% versus 26%) present one or more severe physical symptoms, despite receiving treatment in many cases. Likewise, moderate to severe respiratory distress also increases the probability of hospitalization. Persons with symptoms of confusion or who have severe mobility problems less often stay at home, and are generally living in a care home.

The main aim of home care is to keep the patient comfortable

For the same illness, the objective of treatment and care in the last week of life differs according to the patient's place of residence. People who are hospitalized more often receive curative treatments (62%)[2], while those who stay at home mainly receive palliative care (61%). However, for almost 40% of patients who are hospitalized, comfort is also the main goal; in more than 20% of cases, the transfer is to a palliative care unit. People who die at home less frequently receive psychological support and palliative care. While half of these patients receive care of this kind (versus 7 in 10 among those who are transferred to hospital), 30% of those presenting at least one severe physical symptom do not. Persons transferred to hospital are also more likely to receive continuous artificial nutrition or hydration.

The complexity of treatment often makes home care unfeasible, so a hospital transfer is inevitable. This is the reason for hospitalization most frequently cited (Box 2), notably by family members who do not respect the patient's wish to die at home.

Box 2. A preference for death at home

Questions about where people wish to die and the imminence of death are difficult to discuss with patients and their families. In the "Fin de vie en France" survey, the physician knew the patient's and family's preference in 21% of cases, that of the family alone in 16% of cases and that of the patient alone in 5%. The physicians more frequently knew the patients and their family's preferences (60 %) when the death occurred at home.

Around 55% of the persons whose preferences were know by their physician wished to die at home, 25% in a care home and 17% in a hospital. Among persons who wished to die in hospital, 94% actually did so. For those who wished to die in a care home the proportion was 90%. By contrast, it was just 69% for people wishing to die at home, of whom 25% died in hospital and 6% in a care home. The most frequently cited reason was the complexity of treatment that makes home care unfeasible, rendering a hospital transfer inevitable (76%). Sometimes the death occurs earlier than expected (18%). Last, in 16% of cases, the family did not wish the patient to stay at home, often because of the complex care they needed.

When the physician knows the wishes of both the patient and the family, the two are generally identical (90%). When preferences are different, that of the family generally prevails (82% versus 6%), and only 10% of deaths occur in places that do not correspond to either the family or the patient's wishes.

If the physician only knows the family's wishes, it is generally because the patient is unable to state a preference due to illness (coma, sedation) or mental impairment (confusion, dementia). In such cases, there is a clear family preference for institutional care (in hospital for 55% and in a care home for 31%).

Close family involvement at the end of lifel

The physicians report that family and friends are closely involved at the end of patients' lives.[3] Practically all persons who stay at home or enter hospital (96%) receive visits during their last week of life. Family and friends are more often present at the moment of death when it occurs at home. In 44% of case, only family and friends are present, accompanied by professionals in 26% of cases (versus 26% and 7% for hospitalized patients) (Figure 3). Few home deaths occur in the presence of care personnel only (5%), compared with half of hospital deaths. Last,

(2) Curative treatment (13%) or treatment of one or more severe episodes of a chronic disease (49%).

(3) They have knowledge of it in 80% of cases.

21% of people who die at home are alone at the time of death, versus just 7% of those who die in hospital. Family carers may find it difficult to cope when a relative living at home reaches the end of their life. To ease the burden of carers, the drafting of advance directives should be encouraged, and efforts made to ensure that they are complied with. According to the survey data, however, only 2% of the persons, whether at home or in hospital, had taken this step. Yet when such directives exist, the physicians report that they are an important factor in 74% of the end-of-life medical decisions taken. [7] Only a minority of persons had appointed a trusted third party (around 35%), but in more than 80% of cases this person took part in discussions about end-of-life decisions. For patients at home, the trusted third party is slightly more often a member of the close family circle (partner or child in 89% of cases, versus 80% on average), with very few people appointing the family doctor or another person (0.5% versus 4%). End-of-life decisions made by the physician for persons at home are somewhat less frequently discussed (74% versus 85% on average), but family members are more often involved (63% versus 52%).

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There is a tendency to consider that not all end-of-life situations can be handled at home, the most frequent outcome being a transfer to hospital. The end of life is often medicalized in our society, making hospitalization inevitable. Looking at the last days of life from a more social viewpoint might help to foster a change in attitudes. Indeed, home care is still a neglected component of policies to develop palliative care in France, despite health measures that aim to encourage it, such as hospitalization at home, nursing care in the home, palliative care networks, etc. This observation speaks in favour of stronger support for home care, better training of health professionals, and the development of alternatives to hospital care in the form of new end-of-life care options.

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Abstract

Most people would prefer to die in their own bed, but in fact only a quarter of deaths occur in the home. The "Fin de vie en France" [End of life in France] survey follows the residential and medical trajectories of patients up to their death. In cases of non-sudden death, 45% of persons are living at home four weeks before they die. The most frequent pattern is a move from home to hospital before death (30%); just 14% remain at home throughout the last month of life. A transfer back home from hospital is much less frequent (2%). The complexity of treatment often makes home care unfeasible, so a hospital transfer is inevitable. This is the reason most frequently given for not respecting the patient's wish to die at home.

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Ined: 133, boulevard Davout, 75980 Paris, Cedex 20
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Editor-in-chief: Gilles Pison
Editorial assistant: Marie-Paule Reydet
Translator: Catriona Dutreuilh
Layout: Isabelle Milan
Printer: Jouve, 75001 Paris
D.L. 3th quarter 2015 • ISSN 0184 77 83
No 524 • July-August 2015 • Population & Societies
Monthly bulletin of the French Institute for Demographic Studies

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