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### In France, Where do People Live in Their Last Month of Life and Where do They Die?

The conditions in which people spend their last days of life is an impassioned topic of public debate, but information about these conditions is scarce. What support do family and friends provide in the last weeks of life? What is the extent of medical intervention? How many people die at home? Based on surveys in other European countries, INED conducted a survey among physicians in France who had certified one or more deaths in December 2009. As well as information concerning medical procedures carried out and treatments administered, the survey recorded a precise description of the place where each deceased person was living one month, one week and one day before their death. In this article, the authors analyse the last month of people's lives and show that many move from one place to another during that time. The pattern depends on age and sex, but also varies with type (or types) of pathology and place of residence a month before death. The frequency of transfer to hospital in the days or weeks before death shows that it is difficult for families and care home staff to manage the very last needs of a dying person.

Most deaths in France today occur at advanced or very advanced ages. This is a recent phenomenon in human history, observed only since the twentieth century and only in countries where particularly good progress has been made in combating death and disease. Life expectancy in France has increased

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continuously since 1945 and stood at 78 years for men and 84.6 years for women in 2010. Mortality from birth to care age is now so low that gains in life expectancy are essentially due to declining mortality at advanced ages (Prioux, 2006). This raises the question of whether a new health transition is possible, based especially on closer attention to the day-to-day needs of those in the oldest age groups as a means to further prolong their lives (Vallin and Meslé, 2010).

These changes in mortality patterns are associated with radical changes over the past 50 years in the settings within which people die. The dying process has progressively moved from the private to the public sphere. In 1950 most people died at home, and a majority still did so until the mid-1970s. Since then, institutions, mainly hospitals, have assumed a much larger role (Aouba et al., 2008). In 2009, 58% of deaths in France took place in hospital, 26% at home and 12% in care homes (with or without nursing) (Beaumel and Pla, 2012). France is in an intermediate position among European countries in this regard: in the Netherlands 34% of deaths take place in hospital and 62% in Sweden (Lalande and Veber, 2009; Observatoire national de la fin de vie, 2012).

The proportion of people dying in hospital has remained fairly stable since 1990, while the proportion of home deaths has declined slightly and care home deaths have increased (Monnier and Pennec, 2004; Observatoire national de la fin de vie, 2012). But dying in hospital does not mean that the entire endof-life trajectory takes place there. There is an abundant literature on place and cause of death, but the circumstances in which people spend the last weeks of their life has rarely been investigated in France. Elsewhere, researchers have revealed a wide range of end-of-life trajectories, the most common being a move from home to hospital (Abarshi et al., 2010), and shown the impact of patients' level of independence (Weitzen et al., 2003) and their pathology (Houttekier et al., 2010a, 2010b) on their end-of-life residential trajectory (Escobar Pinzon et al., 2011; Pennec et al., 2012a). As a rule, people with cancer are more likely than other categories to be cared for in hospital, and those with mental disorders in care homes. Other studies have analysed the impact of socio-demographic factors on the likelihood of spending one's last days in this or that type of setting (Gisquet et al., 2012). While there are large variations between countries (Cohen et al., 2006; Gomes, Higginson et al., 2012), many studies have concluded that family care - particularly by the spouse - has a major influence on the likelihood of dying at home (Escobar Pinzon et al., 2011; Gomes and Higginson, 2006; Houttekier et al., 2011).

The "Fin de vie en France" (End of Life in France) survey, conducted in 2010 (Pennec et al., 2012a, 2012b), addresses these issues for France, describing residential trajectories during the last month of life, along with associated factors. The survey was conducted among physicians who had signed death certificates and provided the necessary data to establish end-of-life trajectories, i.e. place of residence 28 days, 7 days and 1 day before death, and on the day

of death. At this stage of life, the places of departure and arrival – home, hospital, care home – are determined by the choices and constraints of the patients and their families and carers. This article examines whether certain demographic or medical factors (age, sex, cause of death, symptoms observed, purpose of treatment, etc.) are associated with particular end-of-life trajectories. What differentiates those who spend their last month of life in familiar surroundings (at home or in a care home) from those who are hospitalized? This analysis of end-of-life circumstances and the linkages between the different care settings over the last month of life will shed new light on the end-of-life process. It will highlight possible limits to the feasibility of keeping people in their homes and will improve understanding of the factors leading to hospitalization at this stage of life.

#### I. Data and methods

The Fin de vie en France survey, conducted by INED,<sup>(1)</sup> was a retrospective study that involved questioning physicians on the circumstances in which patients died. 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. This procedure provided a means to describe what happened to patients shortly before their deaths (Earle and Ayanian, 2006). To limit recall bias, the physicians were questioned less than six months after the deaths they had certified. The protocol was largely inspired by a series of surveys on such issues conducted in Europe since the 1990s to find out more about the decisions taken by physicians treating end-of-life patients (Chambaere et al., 2008; Onwuteaka-Philipsen et al., 2006). The survey procedure provided representative results on the circumstances of people's deaths whether at home, in a care home or in hospital. Other surveys on this subject in France have focused on specific populations, such as users of hospital emergency services (Ferrand et al., 2001; Le Conte et al., 2010).

The initial sample of 14,999 decedents aged 18 and over was drawn by the Centre d'épidémiologie sur les causes de décès (Centre of Epidemiology on Medical Causes of Death, CépiDc) of the Institut national de la santé et de la recherche médicale (National institute of health and medical research, INSERM), and was representative of the 47,872 deaths that had occurred in France in December 2009 in terms of age, sex, place of death and major region.

<sup>(1)</sup> Survey funded by the French Ministry of Health (Direction générale, bureau MC3) and INED, conducted by INED with the participation of the Conseil national de l'Ordre des médecins (French Medical Association), the Centre d'épidémiologie des causes de décès (Centre of Epidemiology on Medical Causes of Death) at INSERM and the Observatoire national de la fin de vie (National end-of-life observatory). For more information see http://fdv.site.ined.fr

For each death certificate in the sample, the certifying physician was sent a paper questionnaire along with information from which to identify the decedent.<sup>(2)</sup> If the certifying physician did not know the patient, the survey protocol allowed them to send on the questionnaire to the physician in charge of the patient, if known. Physicians could respond either by post or online. These channels involved trusted third parties (virtual for Internet responses) to ensure medical confidentiality with regard to the deceased and the anonymity of both the deceased and the physicians taking part in the study. These procedures were approved and authorized by the national data protection authority (Commission nationale de l'informatique et des libertés, CNIL) after approval by the Committee for personal data protection in medical research (Comité consultatif sur le traitement de l'information en matière de recherche dans le domaine de la santé, CCTIRS).

#### Survey participation

In 646 cases, it was not possible to identify the certifying physician. Further, as no physician (other than department heads)<sup>(3)</sup> was asked about more than four deaths even if they had certified more, this gave a final number of 14,080 questionnaires sent out to 11,828 certifying physicians.<sup>(4)</sup> Of that total, 461 did not reach their addressee owing to postal problems or errors in the typing of the physician's name and 5,218 were returned, giving an overall participation rate of 40%.<sup>(5)</sup> This is around the average rate achieved internationally in other surveys (Flanigan et al., 2008; Fox et al., 1989; Joyce et al., 2010; McDonald, 1993; Van Geest and Johnson, 2007). A total of 311 questionnaires were excluded from the analysis because the date of death indicated by the physician was not in December or because the month was missing. The study results are thus based on 4,891 questionnaires or deceased persons.

A telephone survey was conducted among a sample of 620 physicians who had not responded, to make sure the results were representative (sociodemographic profiles of the physicians and reasons for their non-participation). This showed that non-participation had little to do with the survey topic but was due rather to lack of time. The respective profiles of respondent and nonrespondent physicians did not reveal any major distortion that might make

(4) Including 14% who had signed more than one death certificate (only 0.3% signed more than four).

<sup>(2)</sup> i.e. the decedent's date of birth, and date and place of death, which are the only data on the anonymous notification of death available from CepiDc. For reasons of anonymity and to avoid the possibility of data matching, the physicians were required to fill in the socio-demographic characteristics and cause of death on the questionnaire. In addition, the time required to code cause of death from the death certificates meant that this information was not available in time for the sample selection.

<sup>(3)</sup> In line with the Eureld survey methodology, the number of questionnaires was limited to four so that physicians would not refuse to participate. However, because in some hospital departments all death certificates are signed by the consultant, all the questionnaires were sent to him or her, for distribution to the physicians who had actually cared for the patients concerned.

<sup>(5)</sup> Response rate calculated according to the recommendations and tools of the American Association for Public Opinion Research (AAPOR, 2010).

the responses less representative. Whether the physicians had received only one or several questionnaires did not significantly affect the response rate. There were some differences according to speciality and status: the response rate was slightly lower among physicians in private practice than among hospital physicians.

#### Study population

The distribution of places of death in our sample of persons who died in December 2009 was close to that observed for metropolitan France for the whole year (2009) (Beaumel and Pla, 2012). However, there were slightly fewer home deaths (23.2% versus 25.5% for the full year) and deaths in public (or other) places, and slightly more deaths in care homes (15.5% versus 11.6% for the full year). These differences are due to a higher rate of non-response in cases of death from external causes: in these cases death certificates are usually signed by forensic physicians, who did not feel that the survey was relevant to them. The slightly lower response rate from private-practice physicians probably also contributed to the differences.

The sample was also weighted in accordance with the distribution of the initial sample for the available variables: decedent's age, sex, place of death and region of death. The differences between the weighted and unweighted profiles were very small for age and sex, but slightly greater for place of death.

Of the 4,891 deaths observed, 1,589 were reported as "sudden and unexpected" by the certifying physician, which suggests that the patient was not expected to die, so no particular care had been provided. However, the physicians were able to give information about the end-of-life circumstances of 791 of these decedents, so these deaths were included as "non-sudden" in the analysis, bringing the total to 4,093 decedents. Excluding sudden deaths altered the distribution by place of death, since sudden death occurs far more often in the home (51% versus 18% for non-sudden deaths) and far less often in hospital (33% versus 63%) or a care home (7% versus 17%).

Given current mortality patterns and the late mean age at death, the study population is of advanced age, especially as the analysis excludes sudden deaths which, on average, affect younger people: 11% of sudden deaths occurred at under 50 years of age and 44% beyond age 80, versus 4% and almost 60%, respectively, for non-sudden deaths. In addition, due to higher mortality among men (at age 65, a man's life expectancy is a further 18.2 years compared to 22.6 years for women), most men in the sample (almost 2 in 3) died before age 80 while most women died after that age (73% were over 90 years old).

#### Variables used

The survey asked for the decedent's 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: 8% said they did not know where the person was on the day before their death, compared to 11% for 28 days before. All our analyses were performed twice, first taking account of the 16% of missing values and then ignoring them.<sup>(6)</sup> As no major difference between the two sets of results emerged, the figures and tables in this paper do not mention the missing values: their distribution is assumed to be the same as for the known values.

Persons who were in the same place on all available dates were assumed to have been there throughout their last month of life. This maximizes the proportion of persons whose place of residence did not change over those four weeks, since some might have been moved back and forth between two dates. Although such movements are, in principle, most likely to occur over the longest period considered (D-28 to D-7), some studies have shown that moves intensify as death approaches (Abarshi et al., 2010). The later period (D-7, D-1 and D) is well covered in our study, so the bias introduced should be very small.

In line with the literature, the end-of-life trajectories were analysed by age, sex and the patient's medical characteristics: cause of death, the main purpose of treatment during the last week of life, and symptom intensity during the last 24 hours (Tables 1 and 2). These medical variables give only a partial picture of the person's health status. The cause of death may not be the pathology at the origin of the end-of-life trajectory and it is sometimes hard to identify, especially with persons of very advanced age presenting multiple pathologies. There may also be a degree of interpretation in physicians' descriptions of symptom intensity, particularly with patients who are unconscious or communicating little or not at all. Lastly, some information supplied for a particular period (the last 24 hours for symptoms, the last week for purpose of treatment) are assumed to reflect the patient's health status and so potentially have an effect on whether or not they are moved during the last month of life. Imperfect as they are, these questions are commonly used in surveys of this kind (Löfmark et al., 2008; Van der Heide et al., 2003); only by monitoring such patients right up to their deaths could their precise state of health be accurately determined, and this would be difficult to achieve on a representative scale.<sup>(7)</sup>

Little is known about the decedents' family environment. Physicians were only asked to indicate whether, to their knowledge, the family was involved in care of the patient over their last month. Apart from a degree of interpretation in the responses, how much a physician knows about the family's contribution to care doubtless depends on their own degree of involvement in the end-oflife process. Also, in some cases where lack of support is reported, it may be

<sup>(6)</sup> In half of these cases, at least three dates out of four were missing.

<sup>(7)</sup> This survey method is used for death certificates in Belgium and the Netherlands, but only by general practitioners, via sentinel networks (Abarshi et al., 2010, 2011).

| Variable  | Response options   |
|---|--|
| Place of residence  | Hospital (public or private including long-stay<br>units); patient's home; care or convalescent<br>home; nursing home; other   |
| Sex   | Man; woman   |
| Age of decedent   | Under 50; 50-69; 70-79; 80-89; 90+   |
| Underlying cause of death   | Cancer; cardiovascular disease; neurological or<br>cerebrovascular disease; infectious disease;<br>respiratory disease (other than cancer); digestive<br>disease (other than cancer); dementia or mental<br>disorder; death from external causes; other. |
| Purpose of treatment during the last week   | Curative treatment; treatment for an acute<br>episode of a chronic disease; treatment for<br>several acute episodes of a chronic disease;<br>palliative care.  |
| Patient's symptoms in the last 24 hours before<br>death (despite any treatment):<br>Pain, digestive disorders, respiratory distress,<br>depression or anxiety, confusion, mobility<br>problems. | Scale of 0 to 10.<br>Symptoms are considered moderate to severe at a score of 5 or above   |
| Involvement of family and friends in patient's care during the last month of life   | Involved; not involved; involvement not known to the physician.  |

| Table 1. Variables associate | ed with places | of residence a | and of death |
|------------------------------|----------------|----------------|--------------|
|------------------------------|----------------|----------------|--------------|

that the patient does not have, or no longer has, a spouse or children. Despite these limitations, this variable was included in the analyses since the literature review highlights the importance of family support in end-of-life trajectories.

From Table 2, which describes the distribution of responses for the variables used in our analyses, it can be seen that the physicians gave full information on age, sex and cause of death, with a non-response rate of less than 2%. They found it more difficult to describe the purpose of the treatment administered (7% of non-response).<sup>(8)</sup> To obtain more robust results for these last two factors, non-response was imputed on the "nearest neighbour" principle.

#### Methods

Categorical data are given as numbers and as percentages. Polytomous logistic regression was used to measure the effect of each of the variables described above on the likelihood of following a particular trajectory in the last month of life. The regressions compared persons who had changed location (at whatever moment during that month) with those who had spent their entire final month either in hospital, at home or in a care home, the aim being to measure associations between the different variables and types of residential trajectory in the last month of life. All tests were conducted at a significance level of 10% to take account of the small sample size in some categories. Statistical analysis was performed using the SAS software package, version 9.3.

<sup>(8)</sup> Although this rate is around average for this type of question based on a scale of values.

|                       |                             | Weighted<br>total | At home<br>(N = 725) | Hospital<br>(N = 2588) | Care home<br>(N = 694) | Other<br>(N = 68) |
|-----------------------|-----------------------------|-------------------|----------------------|------------------------|------------------------|-------------------|
| 5 ox                  |                             | (N = 4,093)       |                      |                        |                        |                   |
| Man                   |                             | 49.0              | 54.0                 | 52.8                   | 29.5                   | 50.1              |
| Woman                 |                             | 50.6              | 46.0                 | 46.8                   | 70.0                   | 50.1              |
| Non-respons           | ۵                           | 0.4               | 40.0                 | -0.5                   | 0.5                    | 0.0               |
| Total                 | c .                         | 100.0             | 100.0                | 100.0                  | 100.0                  | 100.0             |
| Age                   |                             | 100.0             | 100.0                | 100.0                  | 100.0                  | 100.0             |
| Below 70              |                             | 217               | 25.2                 | 25.6                   | 2.0                    | 413               |
| 70-79                 |                             | 19.5              | 18.1                 | 22.4                   | 10.0                   | 18.1              |
| 80-89                 |                             | 39.8              | 38.6                 | 38.9                   | 45.0                   | 31.7              |
| 90+                   |                             | 18.7              | 17.2                 | 12.9                   | 42.8                   | 9.0               |
| Non-respons           | e                           | 0.4               | 0.9                  | 0.3                    | 0.2                    | 0.0               |
| Total                 |                             | 100.0             | 100.0                | 100.0                  | 100.0                  | 100.0             |
| Cause of death        |                             |                   |                      |                        |                        |                   |
| Cancer                |                             | 31.1              | 30.7                 | 36.0                   | 13.1                   | 37.8              |
| Cardiovascul          | ar disease                  | 21.4              | 30.6                 | 18.2                   | 24.3                   | 15.2              |
| Neurological          | and cerebrovascular disease | 15.6              | 13.6                 | 14.3                   | 23.8                   | 8.2               |
| Infectious dis        | ease                        | 7.4               | 0.8                  | 9.7                    | 5.9                    | 5.2               |
| Respiratory d         | isease                      | 6.5               | 3.9                  | 7.8                    | 4.3                    | 5.0               |
| Digestive sys         | tem disease                 | 4.2               | 2.3                  | 5.4                    | 1.8                    | 3.5               |
| Dementia an           | d mental disorders          | 3.1               | 3.1                  | 1.1                    | 10.7                   | 1.5               |
| Other causes          | i                           | 8.9               | 13.0                 | 6.4                    | 12.9                   | 22.1              |
| Non-respons           | e                           | 1.8               | 2.1                  | 1.2                    | 3.4                    | 1.6               |
| Total                 |                             | 100.0             | 100.0                | 100.0                  | 100.0                  | 100.0             |
| Symptoms duri         | ng the last 24 hours        |                   |                      |                        |                        |                   |
|                       | Moderate or severe          | 11.4              | 11.5                 | 11.4                   | 11.1                   | 14.3              |
| Pain                  | None or slight              | 78.7              | 72.7                 | 80.1                   | 81.2                   | 65.6              |
| - cann                | Non-response                | 10.0              | 15.9                 | 8.5                    | 7.7                    | 20.2              |
| Non-response<br>Total |                             | 100.0             | 100.0                | 100.0                  | 100.0                  | 100.0             |
|                       | Moderate or severe          | 4.8               | 4.5                  | 5.5                    | 2.8                    | 4.9               |
| Nausea                | None or slight              | 84.5              | 79.4                 | 85.1                   | 89.1                   | 72.1              |
|                       | Non-response                | 10.7              | 16.2                 | 9.4                    | 8.1                    | 23.1              |
|                       | lotal                       | 100.0             | 100.0                | 100.0                  | 100.0                  | 100.0             |
|                       | Moderate or severe          | 11.9              | 8.9                  | 13.8                   | 7.9                    | 11.7              |
| Digestive             | None or slight              | //.0              | /4.6                 | /6.4                   | 83.4                   | 65.I              |
| alsoraer              | Non-response                | 100.0             | 16.5                 | 9.8                    | 8.8                    | 23.2              |
|                       | Nederate or severe          | 100.0<br>E2 E     | 100.0                | 100.0<br>E6.4          | E1 0                   | 100.0<br>E1.6     |
|                       | None or clight              | 33.5              | 45.5                 | 20.4                   | 21.0                   | 0.10              |
| Fatigue               | None or slight              | 11.0              | 16.8                 | 10.0                   | 03                     | 27.0              |
|                       | Total                       | 100.0             | 10.0                 | 10.9                   | 100.0                  | 100.0             |
|                       | Moderate or severe          | 39.7              | 28.0                 | 160.0                  | 29.4                   | 28.1              |
| Respiratory           | None or slight              | 51.3              | 56.6                 | 46.4                   | 64.1                   | 54.0              |
| distress              | Non-response                | 9.0               | 15.4                 | 7 4                    | 6.5                    | 17.9              |
| distress              | Total                       | 100.0             | 100.0                | 100.0                  | 100.0                  | 100.0             |
|                       | Moderate or severe          | 13.4              | 13.6                 | 13.3                   | 13.6                   | 17.4              |
|                       | None or slight              | 72.3              | 68.5                 | 72.6                   | 76.5                   | 63.1              |
| Depression            | Non-response                | 14.3              | 18.0                 | 14.1                   | 9.9                    | 19.5              |
|                       | Total                       | 100.0             | 100.0                | 100.0                  | 100.0                  | 100.0             |
|                       | Moderate or severe          | 18.1              | 15.8                 | 19.6                   | 15.1                   | 17.8              |
| A                     | None or slight              | 68.8              | 66.2                 | 68.0                   | 75.6                   | 63.6              |
| Anxiety               | Non-response                | 13.1              | 18.0                 | 12.4                   | 9.3                    | 18.6              |
|                       | Total                       | 100.0             | 100.0                | 100.0                  | 100.0                  | 100.0             |
| [                     | Moderate or severe          | 33.5              | 25.9                 | 32.8                   | 45.1                   | 23.9              |
| Confusion             | None or slight              | 54.5              | 56.8                 | 55.8                   | 47.4                   | 54.7              |
| Contrasion            | Non-response                | 12.0              | 17.3                 | 11.4                   | 7.5                    | 21.4              |
| L                     | Total                       | 100.0             | 100.0                | 100.0                  | 100.0                  | 100.0             |

#### Table 2. Distribution (%) of decedents' characteristics by place of death

|                                     |                             | Weighted<br>total<br>(N = 4,093) | At home<br>(N = 725) | Hospital<br>(N = 2588) | Care home<br>(N = 694) | Other<br>(N = 68) |
|-------------------------------------|-----------------------------|----------------------------------|----------------------|------------------------|------------------------|-------------------|
|                                     | Moderate or severe          | 51.9                             | 43.7                 | 51.7                   | 61.0                   | 51.0              |
| Look of constitu                    | None or slight              | 34.5                             | 38.2                 | 34.8                   | 30.8                   | 27.6              |
| Lack of appetite                    | Non-response                | 13.6                             | 18.1                 | 13.5                   | 8.2                    | 21.4              |
|                                     | Total                       | 100.0                            | 100.0                | 100.0                  | 100.0                  | 100.0             |
|                                     | Moderate or severe          | 73.5                             | 57.0                 | 76.9                   | 79.7                   | 60.8              |
| Mobility                            | None or slight              | 15.3                             | 27.3                 | 12.8                   | 11.7                   | 19.6              |
| problems                            | Non-response                | 11.2                             | 15.7                 | 10.3                   | 8.6                    | 19.7              |
|                                     | Total                       | 100.0                            | 100.0                | 100.0                  | 100.0                  | 100.0             |
| Involvement of f                    | amily and friends in care o | during the last r                | nonth of life        |                        |                        |                   |
| Involved                            |                             | 71.7                             | 69.8                 | 72.8                   | 70.3                   | 65.3              |
| Not involved                        |                             | 8.1                              | 7.1                  | 7.8                    | 10.4                   | 9.6               |
| Not known                           |                             | 11.6                             | 13.0                 | 11.7                   | 8.7                    | 19.2              |
| Non-response                        |                             | 8.6                              | 10.1                 | 7.7                    | 10.5                   | 5.9               |
| Total                               |                             | 100.0                            | 100.0                | 100.0                  | 100.0                  | 100.0             |
| Purpose of treat                    | ment during the last week   | 2                                |                      |                        |                        | -                 |
| Curative                            | 5                           | 7.5                              | 5.0                  | 9.7                    | 2.4                    | 2.3               |
| To treat an acu<br>of a chronic dis | ite episode<br>sease        | 19.2                             | 12.0                 | 22.8                   | 13.8                   | 17.4              |
| To treat severa<br>of a chronic dis | l acute episodes<br>sease   | 17.4                             | 15.0                 | 19.2                   | 14.5                   | 4.0               |
| Palliative care                     |                             | 48.9                             | 53.0                 | 43.5                   | 64.6                   | 56.8              |
| Non-response                        |                             | 7.0                              | 15.0                 | 4.8                    | 4.7                    | 19.5              |
| Total                               |                             | 100.0                            | 100.0                | 100.0                  | 100.0                  | 100.0             |
| Note: Total (4,0                    | )93) includes 18 non-res    | ponses for plac                  | e of death.          |                        |                        |                   |

#### Table 2 (cont'd). Distribution (%) of decedents' characteristics by place of death

Coverage: Non-sudden deaths.

Source: Fin de vie en France survey, INED, 2010.

#### **II. Results**

#### 1. Different end-of-life trajectories

Four weeks before death, by far the most common situation is for people to be living at home – and more so for men (50.6%) than for women (38.3%), who are more frequently living in care homes at that stage (32.1% of women versus 15.8% of men), mainly because more women are widowed.<sup>(9)</sup> However, at this stage of life, similar proportions of men and women are in hospital (about 30%) (Table 3).

As death approaches, there is a shift away from home care to hospitalization. Over the last month of life, the proportion of persons in hospital more than doubles: nearly 70% of men and 60% of women die in hospital, while only 20% of men and 16.3% of women die at home. The proportion in a care home is more stable over these last weeks of life, however, but differs sharply between the sexes: women are slightly more likely to die in a care home (23.4%) than in their own home, while it is by far the least common situation for men (10.5%).

<sup>(9)</sup> The fact that the women in the sample were older is another factor, given that the probability of being institutionalized increases rapidly with age. However, as shown by the literature (Einiö et al., 2012), women more frequently live in an institution than men of the same age, mainly because a higher proportion of them do not have a partner.

| Patient's place of residence  | 28 days<br>before death | 7 days<br>before death | 1 day<br>before death | Day of death      |
|---|-------------------------|------------------------|-----------------------|-------------------|
| Hospital (public or private   | , including long-s      | tay units)             |                       |                   |
| Men   | 32.3                    | 50.3                   | 65.1                  | 68.7              |
| Women   | 28.3                    | 44.0                   | 56.4                  | 59.1              |
| Patient's home  |                         |                        |                       |                   |
| Men   | 50.6                    | 34.3                   | 22.7                  | 20.0              |
| Women   | 38.3                    | 26.3                   | 17.9                  | 16.3              |
| Care home   |                         |                        |                       |                   |
| Men   | 15.8                    | 14.3                   | 11.3                  | 10.5              |
| Women   | 32.1                    | 28.2                   | 24.5                  | 23.4              |
| Other   |                         |                        |                       |                   |
| Men   | 1.2                     | 1.1                    | 0.9                   | 0.8               |
| Women   | 1.2                     | 1.5                    | 1.3                   | 1.2               |
| Total   |                         |                        |                       |                   |
| Men   | 100.0                   | 100.0                  | 100.0                 | 100.0             |
| Women   | 100.0                   | 100.0                  | 100.0                 | 100.0             |
| <i>Interpretation:</i> 28 days be at home.<br><i>Coverage:</i> Non-sudden death | fore their death, 3     | 2.3% of men were       | e in hospital and 5   | i0.6% were living |

#### Table 3. Distribution (%) of places of residence at different dates in the month preceding death

Source: Fin de vie en France survey, INED, 2010.

Between the place of death and the place where the person was living a few weeks earlier, individual trajectories differ widely. While more than half die in the place where they have spent the last month of their life (54.7%, Table 4, "all causes" column), this is more commonly the case for women than for men (58% versus 51%), mainly because more of them are living in care homes. If a patient's place of stay changes at this stage of life, it is usually a transfer to hospital. Some 36.9%, are admitted to hospital at this stage, of whom 29.6% are transferred from their own homes, with 16.8% being hospitalized two to three weeks before death, 11% during the last week of life and about 1.9% on the day of their death. It is far less frequent to move from a care home to a hospital in this last month of life (7.3%), and even more unusual to leave hospital: fewer than 4% do so (2.3% to go home and 1.3% to a care home), especially during the last week of life (0.6%). A small proportion (2.7%) move back and forth between places.

A more detailed observation of residential trajectories over the last weeks of life (Table 5) shows that they vary by place of residence a month before death.

#### Hospital

Most patients who are in hospital a month before death end their lives there (86.4%). This is not always the case, however, and the probability of a

| Trajectory                   | Cancer | Cardio-<br>vascular<br>disease | Cerebro-<br>vascular<br>disease | Infectious<br>disease | Respiratory<br>disease | Digestive<br>disease | Mental<br>disorder | All<br>causes |
|------------------------------|--------|--------------------------------|---------------------------------|-----------------------|------------------------|----------------------|--------------------|---------------|
| Place of residence unchanged | 53.3   | 55.2                           | 60.5                            | 38.7                  | 42.9                   | 35.5                 | 82.5               | 54.7          |
| Hospital                     | 34.3   | 14.4                           | 21.9                            | 26.3                  | 23.5                   | 21.1                 | 14.0               | 23.8          |
| Home                         | 12.3   | 22.1                           | 14.0                            | 0.8                   | 7.8                    | 6.3                  | 15.5               | 14.3          |
| Care home                    | 6.7    | 18.7                           | 24.6                            | 11.6                  | 11.6                   | 8.0                  | 53.0               | 16.5          |
| Home to hospital             | 32.9   | 27.3                           | 28.8                            | 31.9                  | 37.1                   | 47.1                 | 4.0                | 29.6          |
| 2-3 weeks before death       | 22.9   | 12.5                           | 14.0                            | 18.8                  | 18.9                   | 25.5                 | 3.3                | 16.8          |
| One week before death        | 9.1    | 11.2                           | 12.4                            | 11.5                  | 17.0                   | 18.5                 | 0.7                | 11.0          |
| Day of death                 | 0.9    | 3.6                            | 2.4                             | 1.6                   | 1.2                    | 3.1                  | 0.0                | 1.9           |
| Care home to hospital        | 3.4    | 8.3                            | 5.9                             | 21.1                  | 13.4                   | 8.8                  | 2.9                | 7.3           |
| 2-3 weeks before death       | 1.8    | 4.0                            | 2.1                             | 7.2                   | 5.1                    | 1.9                  | 1.8                | 3.1           |
| One week before death        | 0.9    | 3.5                            | 2.9                             | 11.6                  | 7.6                    | 5.5                  | 0.0                | 3.5           |
| Day of death                 | 0.7    | 0.7                            | 0.8                             | 2.4                   | 0.8                    | 1.4                  | 1.1                | 0.7           |
| Hospital to home             | 4.2    | 2.1                            | 1.4                             | 0.4                   | 1.0                    | 2.3                  | 2.1                | 2.3           |
| Hospital to care home        | 1.3    | 1.5                            | 1.2                             | 0.8                   | 0.6                    | 2.4                  | 4.4                | 1.3           |
| Other move                   | 2.8    | 1.0                            | 1.1                             | 2.3                   | 0.9                    | 0.6                  | 1.1                | 1.4           |
| Repeat transfers             | 2.0    | 3.7                            | 1.1                             | 3.9                   | 3.0                    | 2.4                  | 2.1                | 2.7           |
| Overall                      | 100.0  | 100.0                          | 100.0                           | 100.0                 | 100.0                  | 100.0                | 100.0              | 100.0         |
| Coverage: Non-sudden deaths. |        |                                |                                 |                       |                        |                      |                    |               |

Table 4. Distribution (%) of decedents by residential trajectory over the last month of life and by cause of death

Source: Fin de vie en France survey, INED, 2010.

change of place in the weeks before death varies. Slightly more than 5% of persons hospitalized between the 28<sup>th</sup> and 7<sup>th</sup> days before death go home again, and about the same percentage go back to their care home. Between 7 days and 1 day before death, these proportions are 2.9% and 1.2% respectively. Taking into account the unequal duration of these intervals (with a daily transition rate), we see that the proportion of patients returning home increases as death approaches (from 0.2% per day to 0.5%), while the proportion of those going back to their care home remains stable (0.2% per day). Even between the day preceding death and the day of death, 0.4% return home and 0.1% go back to their care homes.

#### Patient's home

People who are living at home a month before their death are the most likely to change their place of residence: less than a third remain at home throughout their last month of life. When they move it is almost always into hospital, and this is increasingly frequent as the month goes by: 39% are hospitalized between the 28<sup>th</sup> and 7<sup>th</sup> days before death, 40.7% between the 7<sup>th</sup> day before death and the eve of death (1.9% and 6.8% per day, respectively).

|                          |  | Hospital    | Home | Care home | Other | Total |
|--------------------------|--|-------------|------|-----------|-------|-------|
|                          | Hospital   | 88.4        | 5.3  | 5.4       | 0.9   | 100.0 |
| Between                  | Home   | 39.0        | 60.4 | 0.5       | 0.1   | 100.0 |
| D-28 and<br>D-7          | Care home  | 14.0        | 0.1  | 85.7      | 0.1   | 100.0 |
|                          | Other  | 22.8        | 2.0  | 0.0       | 75.2  | 100.0 |
|                          | Hospital   | 95.9        | 2.9  | 1.2       | 0.1   | 100.0 |
| Between                  | Home   | 40.7        | 58.8 | 0.2       | 0.2   | 100.0 |
| D-7 and<br>D-1           | Care home  | 17.5        | 0.0  | 82.4      | 0.1   | 100.0 |
|                          | Other  | 18.4        | 0.0  | 5.2       | 76.5  | 100.0 |
|                          | Hospital   | 99.5        | 0.4  | 0.1       | 0.0   | 100.0 |
| Between                  | Home   | 12.8        | 86.8 | 0.0       | 0.5   | 100.0 |
| D-1 and D                | Care home  | 4.4         | 0.0  | 95.6      | 0.0   | 100.0 |
|                          | Other  | 10.5        | 2.9  | 0.0       | 86.6  | 100.0 |
|                          | Hospital   | 86.4        | 8.2  | 4.6       | 0.8   | 100.0 |
| Between                  | Home   | 66.4        | 32.8 | 0.5       | 0.3   | 100.0 |
| D-28 and<br>D            | Care home  | 30.8        | 0.0  | 69.2      | 0.0   | 100.0 |
|                          | Other  | 45.7        | 0.0  | 2.7       | 51.7  | 100.0 |
| Coverage:<br>Source: Fir | Non-sudden deaths.<br>n de vie en France survey, | INED, 2010. |      |           |       |       |

## Table 5. Changes in place of residence between D-28 and D-7, between D-7 and D-1, and between D-1 and D (day of death)

This intensification continues even in the last hours of life, the proportion of patients in hospital increasing by 12.8% between the eve of death and the day itself.

#### Care home

A large majority (69.2%) of persons living in a care home 28 days before their death stay there until they die. Almost none return home<sup>(10)</sup> and any transfer is likely to be to hospital. This occurs at an accelerating pace as death approaches: 17.5% are admitted to hospital in the 7 days preceding their death, a significant increase from the 14% hospitalized in the previous 21 days (0.8% and 2.3% per day, respectively); 4.4% are even hospitalized on the eve of their death.

Although there are large differences between men and women with regard to place of residence one month before death, those living in the same circumstances have similar trajectories. A logistic regression confirms that women are more likely than men to spend the entire period in a care home, but also that they are more likely to be transferred from there to hospital (Table 6).

<sup>(10)</sup> For some, moving into an institution coincides with the sale of their home.

#### 2. Factors associated with different trajectories

#### Age

The proportion of people who are either in hospital or in their own homes 28 days before their death is smaller at the most advanced ages, while the proportion living in care homes is greater: close to zero at age 70, it rises to 50% among those aged 90 and over. This age effect is also found 28 days later with regard to place of death: older people more frequently die in a care home (39% of those aged 90 and over) and more rarely in hospital than younger ones (about 75% before age 80 versus 44% at age 90 and above). By contrast, from the age of 50 on, the likelihood of dying at home varies little with age (by 15-20%). A logistic regression confirms that the oldest age groups are most likely to spend their last month of life in an institution (Table 6 and Appendix Table). Other effects also emerge: being older increases the probability of moving from care home to hospital, but being 90 or over reduces the likelihood of a transfer from home to hospital.

#### Cause of death

Detailed observation of movements from one place to another over the weeks shows the impact of pathology on the end-of-life trajectory (Table 5). People with certain illnesses are more likely than others to spend their entire last month in the same place: hospital in the case of cancer (34.3%) and for those who die of infectious diseases (26.3%); at home for those who die of cardiovascular diseases (22.1%); and in a care home for those with mental disorders (53%) and, to a lesser extent, cerebrovascular diseases (24.6%). Persons whose cause of death is a digestive or respiratory disease or, to a lesser extent, cancer or an infectious disease, are more likely to move from home to hospital (47.1%, 37.1% and about 32-33% respectively). Hospitalization from a care home is more common for those who die of infectious diseases (21.1%) and respiratory diseases (13.4%). The box below also shows that the time spent in hospital before dying there also varies with cause.

Lastly, at this stage of life, patients rarely leave hospital to die at home or in a care home. Moving back home is slightly more common among people who die of cancer (4.2%) and moving back to a care home more common among those who die of mental disorders (4.4%). Cancer is also more often the cause of complex trajectories, particularly repeat transfers (4.8%); this is also the case for infectious diseases (6.2%).

The polytomous analyses designed to measure the effects of the different variables on the probability of a particular residential trajectory confirm this strong association between pathology and end-of-life trajectory (Table 6). The reference population comprises persons who spent the entire last month of life in their homes and the reference cause of death is cancer. By comparison, Table 6. Factors associated with the residential trajectories of patients followed in the last month of life (reference category: at home throughout the month; coefficients and significance tests)

|   |   | No cha   | ange c | of place |       |                                  |         | D                                   | nange ( | of place   |       |            |             |
|---|---|----------|--------|----------|-------|----------------------------------|---------|-------------------------------------|---------|--|-------|------------|-------------|
| Variables   | Categories                              | Hospital |        | Care hom | e     | Transfe<br>from hor<br>to hospit | r<br>al | Transfe<br>from care h<br>to hospit | ome     | Transfer<br>from hospita<br>to home<br>or care hom | e al  | Other tran | sfer        |
| Constant  |   |          |        |          |       |                                  |         |                                     |         |  |       |            |             |
| Sex (ref. men)                                      | Women                                   | 0.20     |        | 0.68     | ***   | 0.07                             |         | 0.55                                | * * *   | 0.01   |       | 0.29       |             |
|   | 70-79                                   | 0.16     |        | 1.98     | ***   | 0.09                             |         | 1.36                                | * * *   | 0.24   |       | - 0.03     |             |
| Age (ref. under 70)                                 | 80-89                                   | 0.08     |        | 2.47     | ***   | 00.0                             |         | 2.13                                | * * *   | 0.21   |       | - 0.01     |             |
|   | 90+                                     | - 0.29   |        | 3.06     | ***   | - 0.45                           | *       | 2.16                                | * * *   | 0.51   |       | - 0.63     | *           |
|   | Cardiovascular disease                  | - 1.32 * | *      | - 0.06   |       | - 1.28                           | ***     | - 0.42                              |         | - 0.78   | *     | - 0.83     | ***         |
|   | Neurological or cerebrovascular disease | - 0.55 * | **     | 0.53     | *     | - 0.35                           | *       | - 0.12                              |         | - 0.78   | *     | - 0.91     | *           |
|   | Infectious disease                      | 2.32 *   | **:    | 2.81     | ***   | 1.82                             | *       | 3.50                                | * * *   | 1.26   |       | 2.42       | ***         |
| Cause of death (ref. cancer)                        | Respiratory disease                     | - 0.08   |        | 0.70     | *     | - 0.34                           |         | 0.76                                | *       | - 0.74   |       | - 0.34     |             |
|   | Digestive disease                       | 0.24     |        | 0.80     |       | 0.46                             |         | 06.0                                | *       | 0.55   |       | - 0.05     |             |
|   | Dementia or mental disorder             | - 1.15 * | **     | 1.16     | **    | - 2.32                           | * * *   | - 1.05                              |         | - 0.11   |       | - 0.79     |             |
|   | Other causes                            | - 1.17 * | **:    | 0.14     |       | - 1.47                           | ***     | - 0.54                              |         | - 1.50   | ***   | - 1.06     | * *         |
| Severity of symptoms durir                          | ng the last 24 hours                    |          |        |          |       |                                  |         |                                     |         |  |       |            |             |
| Pain (ref. none or slight)                          | Moderate or severe                      | - 0.26   | -      | - 0.17   |       | - 0.14                           |         | - 0.39                              |         | 0.37   |       | 0.41       |             |
| Digestive disease<br>( <i>ref</i> . none or slight) | Moderate or severe                      | - 0.08   |        | - 0.27   |       | 0.21                             |         | 0.27                                |         | 60.0   |       | 0.24       |             |
| Respiratory distress<br>(ref. none or slight)       | Moderate or severe                      | 0.14     |        | - 0.21   |       | 0.52                             | * * *   | 0.43                                | *<br>*  | 0.07   |       | 0.68       | *<br>*<br>* |
| Depression or anxiety ( <i>ref.</i> none or slight) | Moderate or severe                      | - 0.07   |        | 0.33     | *     | - 0.18                           |         | 0.54                                | * * *   | 0.12   |       | 0.03       |             |
| Confusion<br>( <i>ref</i> . none or slight)         | Moderate or severe                      | - 0.14   |        | - 0.17   |       | - 0.17                           |         | - 0.29                              |         | 0.25   |       | - 0.01     |             |
| Difficult mobility<br>( <i>ref.</i> none or slight) | Moderate or severe                      | 1.71 *   | *      | 0.94     | * * * | 0.89                             | * * *   | 1.88                                | * * *   | 1.06   | * * * | 0.95       | * * *       |

| Table 6 (cont'd). Factors associated with the residential trajectories of patients followed in the last month of life (reference category: at home throughout the month; coefficients and significance tests) |
|---|
|---|

|   |   | No chang                                | je of place                                 |  | Chang                                       | e of place   |                                    |            |
|---|---|---|---|--|---|--|------------------------------------|------------|
| Variables   | Categories  | Hospital                                | Care home                                   | Transfer<br>from home<br>to hospital   | Transfer<br>from care home<br>to hospital   | Transfer<br>from hospital<br>to home<br>or care home | Other trans                        | fer        |
|   | Curative  | 0.59 **                                 | * 69.0 -                                    | 1.87 ***                               | 1.82 **                                     | + - 0.01   | 1.37                               | * * *      |
| Main purpose of<br>treatment in the last<br>week before death   | Treatment of acute episode<br>of chronic disease  | 0.43 **                                 | 0.21  | 1.60 ***                               | 1.12 **                                     | + - 0.01   | 1.29                               | * * *      |
| (rei. paillative care)  | Treatment of several acute episodes of chronic disease  | 0.52 ***                                | 0.10  | 0.80 ***                               | 1.03 **                                     | * 0.52 *   | 0.66                               | *          |
| Involvement of patient's<br>family and friends in care  | Not involved  | - 0.24                                  | 0.54 **                                     | 0.23                                   | 0.63 *:                                     | * - 2.25 **  | 0.22                               |            |
| during last month<br>(ref. involved)  | Involvement not known to physician  | - 0.65 ***                              | 0.16  | 0.23                                   | 1.39 **                                     | *  | - 0.80                             | *          |
| Note: The model is a polytom<br>covers all complex trajectorie:<br>effect)  | to be logistic regression illustrating the difference.  | nt trajectories del<br>few observed cas | fined by place of r<br>ses. There is no lin | esidence at D-28,<br>ear connection be | D-7, D-1 and day of<br>etween the exogenc   | death. The "Other trans                              | ansfers" catego<br>es (no colinear | ity v      |
| <i>Interpretation</i> : Coefficients<br>of life rather than remaining<br>exp(2.47) = 11.8 times greate<br><i>Significance levels</i> : * 10%; | are interpreted as the effect of a unit increas<br>at home over the entire month. For perso<br>er than for persons aged 70 and under. | e in the variable<br>ns aged 80-89,     | considered on the<br>the probability o      | e probability of ha                    | ving a given type of<br>ntire month in a ca | residential trajectory<br>re home rather than        | in the last mon<br>in own home     | ith<br>is: |
| Coverage: Non-sudden deat   | ris.<br>survev INED 2010  |   |   |  |   |  |                                    |            |

# Time spent in hospital in the last four weeks of life before dying there

Although nearly two in three people die in hospital, an analysis of trajectories during the last month of life gives a more nuanced picture. Death occurs after varying lengths of time in hospital: 39.3% of those who die in hospital have been there for a month or more, a third have spent the past three weeks there, and 28% are only hospitalized in their last week of life (Table A). Duration of hospital stay in the last month of life varies with cause of death. Of patients with mental disorders who die in hospital, 67.1% have spent the previous month there. Cancer patients dying in hospital are also likely to have been there for some time: 48.6% for a full month, with only 16.4% arriving a week or less before death. By contrast, those who die in hospital of cardiovascular, respiratory or digestive diseases are often moved to hospital shortly before death: 36-38.1% are admitted in the last week of life.

| Tal | ble A. Du<br>fo | urat<br>or pa | ion c<br>atien | of ho<br>ts w | spital<br>ho di | stay<br>e the | re, b | ing<br>/ ca | the la<br>use of | st m<br>deat | onth<br>th | n of l | ife |  |
|-----|-----------------|---------------|----------------|---------------|-----------------|---------------|-------|-------------|------------------|--------------|------------|--------|-----|--|
|     |                 | -             |                |               |                 |               |       |             |                  |              |            |        |     |  |

|   | Cancer                                 | Cardio-<br>vascular                        | Cerebro-<br>vascular                  | Infectious<br>disease | Respiratory<br>disease | Digestive<br>system | Mental<br>disorder | All<br>causes |
|---|--|--|---------------------------------------|-----------------------|------------------------|---------------------|--------------------|---------------|
| 4 weeks   | 48.6                                   | 28.7                                       | 38.8                                  | 33.2                  | 31.7                   | 27.4                | 67.1               | 39.3          |
| 1-4 weeks   | 35.0                                   | 33.1                                       | 28.5                                  | 32.7                  | 32.3                   | 35.6                | 24.1               | 32.7          |
| 1 week or less  | 16.4                                   | 38.1                                       | 32.7                                  | 34.1                  | 36.0                   | 36.9                | 8.8                | 28.0          |
|   | 100.0                                  | 100.0                                      | 100.0                                 | 100.0                 | 100.0                  | 100.0               | 100.0              | 100.0         |
| * Estimated ma<br>to have stayed<br><i>Source:</i> Fin de | ximum dui<br>there thro<br>vie en Frar | ration: perso<br>ughout the<br>nce survey, | ons reported<br>month.<br>INED, 2010. | in the same           | place on all fo        | our available       | e dates are        | assumed       |

all other things being equal, dying of an infectious disease is associated with a higher probability of being in hospital either for the last month of life or for a shorter period. This cause of death is also associated with a higher probability of staying in a care home throughout. With mental disorders, the likelihood of spending the entire month in a care home is higher, and that of being in hospital for the full month or transferred to hospital at a later point is lower. Lastly, dying of cerebrovascular or cardiovascular disease is associated with a lower probability of hospitalization, whether for the whole month or for a shorter stay.

#### Symptoms observed in the last 24 hours before death

The survey describes the symptoms observed in the 24 hours before death despite treatment, if any. These are an illustration of the severity or degree of progression of a disease. Whether treated in hospital, at home or in a care home, about 18% of people present moderate to severe symptoms of depression and/or anxiety and 11% experience pain (Table 2). Most other symptoms are usually less severe in persons who stay at home until they die. By contrast, those who die in hospital more often have serious symptoms, particularly

mobility problems (77%), respiratory distress (46%) and digestive disorders (14%). Those who die in care homes present very specific symptoms: mobility problems (79.7%) and confusion (45.1%).

These contrasting situations are confirmed by a logistic regression. When individual and medical characteristics are held equal (Table 6), those with respiratory distress and digestive disorders in the last 24 hours of life are more likely to have been hospitalized during their last month of life. Mobility problems, probably too difficult to manage at home, are associated with a higher probability of institutional care (continuous or for a shorter period) in hospital or a care home. Dementia increases the probability of staying in a care home or being taken to hospital from there.

#### Type of treatment in the last week

Type of treatment differs according to the patient's place of residence. Treatment at home or in a care home is far more often palliative (66-68% on average versus 52% in hospital – Figure 1). Transfers to hospital in the last week of life are more often intended to treat one or more acute episodes of a chronic disease (50-57% versus 39%) or to provide curative treatment (average 15-16% versus 8%).

The purpose of treatment varies widely depending on the disease that is to prove fatal. For cancer and cerebrovascular diseases, two of the most frequent pathologies, and for mental disorders, physicians virtually exclude the possibility of a cure<sup>(11)</sup> and the main aim of treatment is to provide palliative care (78%,



#### Figure 1. Purpose of treatment during the last week of life, by place of residence (%)

<sup>(11) 5.7%</sup> for cases of cerebrovascular disease, 1.4% for mental disorders and 1.2% for cancer.

63% and 75% of cases respectively). For the other diseases, the main aims are to treat acute episodes (about 60% of cases) or to provide palliative care (20-30%). Curative treatment is considered more rarely, though more often than with the aforementioned diseases (ranging from 11% for cardiovascular diseases to 21% for digestive diseases).

The logistic regression confirms that different places of residence are associated with specific types of treatment. The likelihood of hospitalization from either home or care home increases when the aim is to provide curative treatment rather than palliative care, or to treat one or more acute episodes of a chronic disease (Table 6).

#### Involvement of family and friends during the last month of life

Whatever the residential trajectory in the last month of life, the responding physicians observed that family and friends are generally involved in patient care. However, their knowledge of the patient's family situation is variable: they are most frequently able to describe it when all or part of the end-of-life period is spent in hospital (91% versus around 80% for patients remaining at home or in a care home). For patients who are transferred from hospital to their own home, physicians report family care in 99% of cases. Persons who spend the last month of life in hospital slightly more frequently receive family care (94%) than those remaining at home (87%) or in a care home (89%). These high percentages for all places of residence are evidence of the strong involvement of family and friends at this stage of life.

If differences in patient characteristics are taken into account in the logistic regression it emerges that patients with no family support are more likely to spend the last month of life in a care home or to be hospitalized from there, and less likely to leave hospital to end life at home or in a care home (Table 6).

#### Conclusion

Three out of five people die in hospital, but only half are hospitalized a month before their death. Between these two dates, the most frequent transfer is to hospital from the patient's home. This tallies with findings in other European countries (Abarshi et al., 2010; Higginson et al., 2010). By contrast, most people living in care homes or already hospitalized remain in the same place until death. The frequency of transfers to hospital, whether from home or a care home, increases as death approaches. This is also found in other studies (Klinkenberg et al., 2005; Van den Block et al., 2007) and probably reflects the difficulty, for family or friends, and for staff in some care homes, of managing this final stage of deterioration in health.

Age and sex strongly influence the end-of-life trajectory. Women and the very elderly are most likely to spend their last month of life in a care home,

and are also most frequently transferred from there to hospital. This is probably because they are more often affected by disabling multiple pathologies and/or - since women are more frequently widowed, and carers may themselves be elderly - are living in less secure family or social environments with smaller networks of potential carers (Désesquelles and Brouard, 2003). There is an abundant literature on the support provided by the family during the last weeks of life (Escobar Pinzon et al., 2011; Gomes and Higginson, 2006; Houttekier et al., 2011). One limitation of our survey is that the information it provides on this aspect is very incomplete, based only on the physicians' testimonies. Other involved parties or witnesses - patients, their families and other medical workers - might present a different viewpoint. Despite these limitations, the physicians' observations tally with the literature: whatever the place of residence, the family is present during the last weeks of life in the great majority of cases. Those who do not have the support of family or friends are less likely to be transferred from hospital to die at home or in a care home, and are more likely to spend the last month of their life in a care home. It is known that mutual support between spouses is a key factor for keeping a patient at home (Soullier and Weber, 2011), as indicated by the very low rate of admission of married people to institutions and women's high rate of admission owing to their high incidence of widowhood. In future, the marked decrease in widowhood thanks to declining mortality rates and the narrowing of the mortality gap between men and women will mean that people of advanced age, women especially, will more often spend their old age with a partner (Gaymu et al., 2008). As a result, old people, women especially, should die more often at home and less often in care homes.

However, the expected changes in disease structure could operate against this trend. We have shown that end-of-life trajectories vary widely with pathology. Particular pathologies are linked to higher probabilities of spending the last month of life in a particular place: hospital for cancer patients, the home for those who die of cardiovascular disease, care home for those with mental disorders. In other cases, death may take place in hospital after varying lengths of stay. Unlike cancer patients, people who die of infectious, cardiovascular, respiratory and digestive diseases more often go into hospital in the last week of life. However, the structure of causes of death has been changing over recent decades. The sharpest decline has been in mortality from cardiovascular diseases. Cancer mortality has also declined, though less sharply, and cancer is today the leading medical cause of death. Infectious, respiratory and digestive diseases also continue to decline and their contribution to total mortality is now very minor. By contrast, mortality from nervous system diseases and mental disorders, which particularly affect the most advanced ages, has risen rapidly (Mazuy et al., 2011). If these trends continue, people will increasingly spend their last days in institutions, since the great majority of cancer victims spend the last weeks of their lives in hospital and those suffering from mental disorders in care homes. If there are no notable changes

in treatments for these diseases or in care arrangements, these trends will raise future demand for hospital beds and for places in care homes.

These structural changes could be counterbalanced by individual preferences and/or particular policy measures. Although surveys on individual preferences regarding place of death should be treated with caution,<sup>(12)</sup> they show that in France, as elsewhere, most people express a wish to die at home (Beuzart et al., 2003; Gomes, Higginson et al., 2012; Higginson et Sen-Gupta, 2000). Despite the development of health policies designed to encourage home care (hospitalat-home programmes, home nursing services, mobile palliative care networks, etc.), France's palliative care policies make scant provision for this option. Our study shows that not all situations are manageable at home and that patients at this stage in life rarely leave hospital to die at home or in a care home.<sup>(13)</sup> A transfer to hospital in the last month of life is most likely where the purpose is to offer curative treatment or to treat an acute episode of a chronic disease, and in cases of respiratory distress or mobility problems. But 24 hours before death, the likelihood of presenting symptoms of moderate to severe depression or anxiety (about 20%), or pain (11%), are the same whether the patient is in hospital, a care home or their own home, even if they are given treatment. While it is difficult to judge any differences in the quality of symptom management between home, hospital and care home from these results (since hospital cases are probably more severe), the symptom levels observed are evidence of the need for more effective management. This argues for better training of healthcare workers, greater support for home care when desired, and increased provision of alternatives to hospitalization, with new places for end-of-life care. In the United Kingdom, dying at home has become slightly more common in recent years, particularly following the introduction of specific policies such as the National End of Life Care Initiative/Strategy (Gomes, Calanzani et al., 2012).

Some methodological limitations have already been discussed in this article. The survey was a retrospective one based on the observations of physicians, not all of whom had full knowledge of the trajectories they describe. Despite their high degree of involvement, as reflected in the high response rate for most of the questions on end-of-life circumstances, the physicians' answers were necessarily partly subjective, particularly their assessments of symptom severity and of family involvement. Moreover, information on place of residence was available for only four dates during the last month of life, and information on some variables only covered a particular period (symptoms in the last 24 hours, purpose of treatment in the last week). As a result of these limitations, our analysis of the end-of-life trajectory and the associated factors lacks

<sup>(12)</sup> Particularly because they are strongly influenced by the way the questions are formulated (Bell et al., 2010).

<sup>(13)</sup> Except for the first transfer in the case of cancer, and the second in the case of mental disorders (about 4%).

precision, although our results are in line with the existing literature. But proper monitoring of the end-of-life care process, linking the emergence and worsening of symptoms with the date of hospitalization, for example, would require a different survey method encompassing all persons involved with patients in their last days, which is scarcely feasible on a representative scale. Further, despite the large overall sample size, some trajectories were poorly represented, particularly transfers from hospital, and this prevented us from identifying more complex links between variables than the ones modelled here.

Despite these limitations, the study shows that place of death is conditioned by type of disease and purpose of treatment over the last month of life, some clinical situations making it impossible to care for the dying at home. In the next few decades the number of deaths and of the dying, particularly those at very advanced ages, will increase markedly as the baby-boom generations reach ages where mortality is high (Monnier et Pennec, 2004). This more obvious presence of death in society may make new demands on public policy, and questions about the nature of palliative care and the place of care at the end of life may present themselves with greater urgency.

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#### **APPENDIX**

Mean of probabilities estimated by the polytomous model (coefficients of Table 6) on the overall population (average marginal effect)

|                       |   |                     |                   |              | Trajec                            | cories   |           |                        |         |
|-----------------------|---|---------------------|-------------------|--------------|-----------------------------------|----------|-----------|------------------------|---------|
|                       |   | Other<br>trajectory | Home/<br>hospital | Home         | Hospital/<br>home or<br>care home | Hospital | Care home | Care home/<br>hospital | Overall |
| Sex                   | female                                  | 4                   | 27                | 12           | Ω                                 | 24       | 21        | 6                      | 100     |
|                       | male                                    | 4                   | 37                | 14           | С                                 | 27       | 6         | 9                      | 100     |
| Age                   | below 70                                | ъ                   | 43                | 15           | m                                 | 31       | -         | -                      | 100     |
|                       | 70-79                                   | 4                   | 37                | 12           | ŝ                                 | 30       | 00        | ß                      | 100     |
|                       | 80-89                                   | 4                   | 30                | 12           | ŝ                                 | 24       | 16        | 11                     | 100     |
|                       | +06                                     | 2                   | 17                | 13           | 4                                 | 16       | 35        | 12                     | 100     |
| Cause of death        | cancer                                  | 5                   | 35                | 11           | ß                                 | 36       | 9         | m                      | 100     |
|                       | cardiovascular disease                  | 5                   | 29                | 21           | m                                 | 15       | 18        | 6                      | 100     |
|                       | digestive disease                       | c                   | 49                | 5            | 4                                 | 23       | 7         | б                      | 100     |
|                       | respiratory disease                     | 4                   | 38                | 7            | 1                                 | 25       | 10        | 15                     | 100     |
|                       | infectious disease                      | 9                   | 33                | <del>~</del> | 1                                 | 28       | 10        | 21                     | 100     |
|                       | neurological or cerebrovascular disease | 2                   | 31                | 12           | 2                                 | 23       | 22        | 9                      | 100     |
|                       | dementia or mental disorder             | M                   | ß                 | 15           | 9                                 | 16       | 53        | m                      | 100     |
| Pain                  | moderate to severe                      | 7                   | 32                | 13           | 9                                 | 23       | 12        | 7                      | 100     |
|                       | none or slight                          | 4                   | 32                | 13           | Э                                 | 26       | 15        | 8                      | 100     |
| Digestive disorder    | moderate to severe                      | 9                   | 39                | 6            | 4                                 | 22       | 6         | 10                     | 100     |
|                       | none or slight                          | 4                   | 31                | 13           | С                                 | 26       | 16        | 7                      | 100     |
| Respiratory distress  | moderate to severe                      | 5                   | 37                | 6            | Μ                                 | 24       | 11        | 10                     | 100     |
|                       | none or slight                          | Э                   | 28                | 16           | ю                                 | 26       | 18        | 6                      | 100     |
| Anxiety or depression | moderate to severe                      | 5                   | 33                | 12           | D                                 | 26       | 12        | 7                      | 100     |
|                       | none or slight                          | 4                   | 31                | 13           | m                                 | 25       | 16        | 00                     | 100     |

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|  |  |                                   |                                      |                                    | Irajeci                           | cories        |                 |                        |             |
|  |  | Other<br>trajectory               | Home/<br>hospital                    | Home                               | Hospital/<br>home or<br>care home | Hospital      | Care home       | Care home/<br>hospital | Overall     |
| Confusion  | moderate to severe   | 4                                 | 27                                   | 10                                 | 4                                 | 25            | 19              | 11                     | 100         |
|  | none or slight   | 4                                 | 34                                   | 14                                 | m                                 | 26            | 12              | 9                      | 100         |
| Mobility problems  | moderate to severe   | 4                                 | 30                                   | 10                                 | m                                 | 28            | 15              | 6                      | 100         |
|  | none or slight   | 4                                 | 39                                   | 28                                 | 2                                 | 12            | 12              | 4                      | 100         |
|  | curative   | 4                                 | 53                                   | 10                                 | -                                 | 15            | m               | 13                     | 100         |
| Purpose of treatments  | treatment of an acute episode of a chronic disease   | 9                                 | 46                                   | 6                                  | 2                                 | 17            | 11              | 10                     | 100         |
| in last week   | treatment of several acute episodes of<br>a chronic disease  | 4                                 | 29                                   | 12                                 | 4                                 | 26            | 13              | 12                     | 1 00        |
|  | palliative   | m                                 | 23                                   | 15                                 | 4                                 | 30            | 19              | ß                      | 100         |
| Involvement of family<br>and friends in patient<br>care during the last<br>month of life                   | involved   | 4                                 | 31                                   | 13                                 | 4                                 | 28            | 15              | Q                      | 100         |
|  | not involved   | Ð                                 | 35                                   | 14                                 | 0                                 | 17            | 20              | 6                      | 100         |
|  | physician does not know  | 2                                 | 37                                   | 15                                 | 1                                 | 11            | 12              | 22                     | 100         |
| Overall total  |  | 4                                 | 32                                   | 13                                 | m                                 | 25            | 15              | Ø                      | 100         |
| Interpretation: The unw<br>and 5% for those who di<br>Coverage: Non-sudden d<br>Source: Fin de vie en Fran | eighted mean of the probabilities of a tran<br>e from mental or psychiatric disorders, the<br>eaths.<br>ce survey, INED, 2010. | sfer from home<br>overall value o | e to hospital in<br>if the other var | i the last mont<br>riables being e | h of life predict<br>qual.        | ed by the mod | el is 35% for p | ersons who die         | from cancer |

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#### Sophie PENNEC, Joëlle GAYMU, Alain MONNIER, Françoise RIOU, Régis AUBRY, Silvia PONTONE, Chantal CASES • IN FRANCE, WHERE DO PEOLE LIVE IN THEIR LAST MONTH OF LIFE AND WHERE DO THEY DIE?

This article describes the residential trajectories and places of residence of patients over their last month of life, based on the end-of-life survey "Fin de vie en France", conducted in 2010 on a representative sample of deaths occurring in December 2009. The physicians who had certified the deaths were questioned about the end-of-life circumstances. While three in five people die in hospital, only half were in hospital a month before their death. Over that last month, the most common move is from home to hospital. Those already in hospital or living in a care home a month before death are very likely to remain there until they die. Multivariate analyses show that age and sex influence the end-of-life trajectory: it is the oldest individuals, and women, who are most likely to spend their last month in a care home. Symptoms, type of disease and purpose of treatment also play a role. Not all clinical situations can be handled through home care: treatment of acute episodes, respiratory distress and digestive problems are more often treated in hospital, mental disorders in care homes and mobility problems in both these places.

#### Sophie PENNEC, Joëlle GAYMU, Alain MONNIER, Françoise RIOU, Régis AUBRY, Silvia PONTONE, Chantal CASES • LE DERNIER MOIS DE L'EXISTENCE : LES LIEUX DE FIN DE VIE ET DE DÉCÈS EN FRANCE

Cet article décrit les lieux de vie et trajectoires résidentielles des personnes durant le dernier mois de leur existence, à partir de l'enquête *Fin de vie en France* réalisée en 2010. L'enquête repose sur un échantillon représentatif des décès survenus en décembre 2009. Les médecins ayant certifié les décès ont été interrogés sur les circonstances de la fin de vie. Si 3 personnes sur 5 meurent à l'hôpital, seules la moitié étaient hospitalisées un mois avant leur décès. Dans ce laps de temps, l'hospitalisation à partir du domicile est le changement le plus fréquemment observé. Les personnes prises en charge en maison de retraite ou à l'hôpital un mois avant leur décès ont une forte probabilité d'y finir leurs jours. Des analyses multivariées montrent que l'âge et le sexe influencent le parcours de fin de vie : ce sont les plus âgés et les femmes qui présentent le plus fort risque de vivre leur dernier mois en maison de retraite. Les symptômes, le type de maladies et la finalité des traitements conditionnent les lieux de la fin de vie des patients. Toutes les situations cliniques ne permettent pas de maintenir les personnes de souvent traités à l'hôpital, les troubles mentaux en maison de retraite et les difficultés de déplacement dans chacun de ces lieux.

#### Sophie PENNEC, Joëlle GAYMU, Alain MONNIER, Françoise RIOU, Régis AUBRY, Silvia PONTONE, Chantal CASES • EL ÚLTIMO MES DE LA VIDA: LOS LUGARES DE FINAL DE VIDA Y DE DEFUNCIÓN EN FRANCIA

Este artículo describe los lugares de vida y las trayectorias residenciales de las personas enfermas, durante su último mes de vida, a partir de la encuesta *El final de la vida en Francia* realizada en 2010. La encuesta se basa en una muestra representativa de las defunciones sucedidas en diciembre de 2009. A los médicos que certificaron las muertes se les preguntó sobre las circunstancias del fin de vida. Si 3 de cada 5 personas mueren en el hospital, sólo la mitad estaban hospitalizadas un mes antes de su muerte. Durante este plazo, el desplazamiento del domicilio al hospital es el cambio más frecuentemente observado. Las personas atendidas en una residencia de ancianos o en un hospital un mes antes de su muerte, tienen una alta probabilidad de acabar allí sus días. Los análisis multivariados muestran que la edad y el sexo influyen en el recorrido del fin de vida: son los más viejos y las mujeres los que presentan un mayor riesgo de pasar su último mes de vida en una residencia de ancianos. Los síntomas, el tipo de enfermedad y la finalidad de los tratamientos condicionan los lugares donde los pacientes van a terminar su vida. No todas las situaciones clínicas permiten tratar a las personas su casa: el tratamiento de episodios agudos, las dificultades respiratorias o los problemas digestivos son más frecuentemente tratados en el hospital, los problemas mentales en las residencias de ancianos y las dificultades de desplazamiento en cada uno de estos sitios.

**Keywords:** end of life, death, place of death, France, life course, home, care home, hospital.

Translated by Harriet Coleman.