End-of-life care and preferences for (non)treatment decisions in older people during their last three months of life
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CHAPTER 2

CHANGES OVER A DECADE IN END-OF-LIFE CARE AND TRANSFERS DURING THE LAST THREE MONTHS OF LIFE: A REPEATED SURVEY AMONG PROXIES OF DECEASED OLDER PEOPLE

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ABSTRACT

BACKGROUND: In the ageing population, older people are living longer with chronic diseases. Especially in the last year of life this can result in an increased need for (complex) end-of-life care.

AIM: To study potential changes in received end-of-life care and transfers by older people during the last three months of life between 2000-2010.


PARTICIPANTS: Data were collected from a sample of proxies of deceased sample-members of the Longitudinal Aging Study Amsterdam (LASA) in 2000 (n=270, response 79%) and 2010 (n=168, response 59%).

RESULTS: Compared to 2000, in 2010 older people had a significantly lower functional ability three months before death. Over the ten-year period, people were significantly less likely to receive no care (12% versus 39%) and more likely to receive formal home care (45% versus 17%). Older people aged over 80, females and those in the 2010 sample were more likely to receive formal home and institutional care (formal home care: age>80 OR 3.7, male OR 0.74, 2010: OR 6.9; institutional care: age>80 OR 11.6, male OR 0.34, 2010: OR 2.5), than informal or no care. Regardless of study year, older people receiving informal home care, were more likely to die in hospital (OR 2.3).

CONCLUSION: Two scenarios of care in the last three months of life seem to arise: staying at home as long as possible with a higher chance of hospital death or living in a residential or nursing home, reducing the chance of hospital death.

KEYWORDS end-of-life care, transfers, older people, institutionalisation, formal home care, informal home care, hospital death, place of death, functional ability
INTRODUCTION

As a result of the population ageing, people are living longer with chronic diseases. Additionally, older people are frequently affected with multiple medical problems, many of which arise predominantly in the last year of life. Consequently, there is an increased need for care over a longer period of time, and particularly for more complex care closer to death. This care can be given by family or friends (informal care) or by professionals (formal care), and can be provided in an institution or at older people’s homes. The likelihood of older people receiving institutional care, is influenced by age and functional ability. About ten years ago, more than one third of Dutch older people received institutional care and another 16% received formal home care in the last months of life. A further increase in institutionalization has been predicted.

It is of interest to study place of care in the last phase of life considering that most people prefer to be cared for and die at home. Several studies have shown that supporting more home care opportunities by avoiding institutionalization may reduce health care costs. However, research has also shown that many people are transferred to a hospital and die there instead of their preferred own home. A study on care arrangements of older Dutch people revealed that in the 1990’s half of the Dutch older population experienced one or more transfers between care settings in the last three months of life and 32% died in a hospital. Furthermore, 17% died in a nursing home and 15% died in a residential home.

Changes in care may origin from demographic changes of the population as well as changes in health care services. We replicated the study of ten years ago, in order to study potential changes in received care by older people during the last three months of life between 2000-2010. Specific objectives are to study place of residence, transfers between care settings and place of death. Furthermore, we examined factors associated with type of care received and with dying in hospital.

METHODS

Study design and sample

The data were derived from deceased sample members of the Longitudinal Aging Study Amsterdam (LASA). The LASA cohort is based on a national representative sample of older adults aged 55-85 years, stratified by age and gender and drawn from three regions in the Netherlands. These regions reflect the national distribution of urbanisation and population density. The representativeness of the LASA cohort was examined by comparing mortality in the LASA sample to that in the Dutch population: the mortality difference observed between
LASA and the Dutch population was less than 1%, except for all groups except women aged 80-85. In 1992-1993 the LASA sample was recruited (T1) and a total of 3107 subjects were enrolled. Data collection takes place every three years. An additional cohort was recruited from the sampling frame in exactly ten years after the first cycle of the cohort (n=1002 enrolled in 2002-2003). The sampling, data-collection and response rates of the LASA have been described more extensively elsewhere.

For our study we sampled all deceased LASA sample members who had died between 1995-1999 (T2-T3) and 2005-2009 (T5-T6, including the new cohort) and who had given permission to contact a named proxy. This proxy was contacted for participation. After confirmation of participation, data was obtained through a structured interview based on a standardized questionnaire in 2000, and through a written questionnaire in 2010. In this article the description ‘the 2000 sample’ refers to members who died between 1995-1999 and ‘the 2010 sample’ refers to members who died between 2005-2009. The samples enclosed all deaths, including sudden deaths, since it is not very well possible to let proxies distinguish between sudden- and non-sudden deaths in a uniform way. Their proxies filled in the questionnaire in 1999-2000 and 2009-2010. The study design was approved by the Medical Ethical Committee of the VU University Medical Centre.

The 2000 sample consisted of 342 deceased LASA sample members. We approached 325 proxies since 17 proxies (5%) could not be found. A total of 270 proxies completed and returned the questionnaire (79%), 25 proxies (8%) did not respond and 30 proxies (9%) refused participation. The 2010 sample included 311 deceased LASA members. 284 proxies were approached since 27 proxies (10%) could not be found. A total of 168 proxies completed and returned the questionnaire (59%), 69 proxies (25%) did not respond and 47 proxies (17%) refused participation.

In the 2000 sample 47% of the respondents were children of the deceased, and 32% the deceased’s partner. In the 2010 sample 78% were a child of the deceased and 7% the partner. For both time periods, no significant differences were found in type of proxy between respondents and non-respondents.

**Measures**

The questionnaire consisted of structured questions about socio-demographic characteristics, symptoms, functional ability, types of care, transfers and place of death. Symptoms included somatic complaints (e.g. pain and other physical symptoms) and psychosocial complaints (e.g. mood) during the last week before death. Severity of symptoms was rated on a 3-point scale in 2010: ‘no symptoms, not very severe and very severe symptoms’. Similar questions
included a 4-point scale in 2000 (‘no symptoms, symptoms not severe, symptoms, relatively severe, very severe symptoms’). A mean score of severity was used. To ensure comparability of mean scores the 2000 scale was recoded into the 3-point scale (the options not severe and relatively severe were combined in ‘not very severe symptoms’).

Functional ability was measured with questions about five activities three months and three days before death and the answering options ranged from 1 to 5 (‘not possible’ (1) to ‘yes, without difficulty’ (5)). A sum score was calculated, with scores ranging from ‘respondent was unable to perform any of the activities of daily living (5)’ to ‘respondent was able to perform all activities without difficulty (25)’. 31

Type of care three months and three days before death was distinguished in informal home care, formal home care or institutional care. Care refers to help with personal care (washing, bathing, dressing, toileting, transferring) and not to help with household (e.g. cooking, shopping). Informal home care was defined as care provided by one or more unpaid family members, friends or acquaintances. Formal home care was defined as care provided by one or more paid and professionally trained caregivers (e.g. registered nurses). Institutional care was defined as living in facilities such as residential/nursing homes, hospitals and hospices.

Transfers to different types of care arrangements are rated from lower to higher intensity of care. The hierarchy was defined as home, residential home, nursing home and hospice or hospital.

Analyses
The 2000 and 2010 data were pooled. The oldest member of the 2000 sample was 91 years old compared to 100 years old for the 2010 sample. To ensure that age did not influence the comparison between the 2000 and 2010 sample, the sampling age was restricted to a range of 55-91 years for both samples. To make the two samples comparable and the estimates interpretable the data of both samples were weighted by age and gender. As reference, we looked at age and gender distribution of deaths in the Netherlands in 2008, a central year of death for people the 2010 sample. These numbers were derived from mortality of Statistics Netherlands 1. Differences between both samples in patient characteristics, symptoms and care characteristics were tested with chi-square tests and t-tests.

Multinomial analysis was conducted for type of administered care and as independent variables age, gender, education, marital status, functional ability and year of measurement. Age, gender and year of measurement were forced in the analyses, as these variables are essential to the overall aim of the study. Others were stepwise removed if p > 0.05. Potential
interaction between age and year of measurement, and gender and year of measurement was checked, and found to be not significant.

Multivariate logistic regression analyses were performed to identify variables associated with dying in a hospital. First, univariate logistic regression was conducted and all significant variables were included in stepwise backwards multivariate logistic regression. Age, gender and year of measurement were forced in the analyses. Others were removed if $p > 0.05$. Independent variables were education, marital status, functional ability, care arrangement and cancer. Potential interactions between care arrangement on the one hand, and year of measurement, functional ability and cancer on the other hand were checked and found to be not significant.

RESULTS

General characteristics
About half of the sample was people over 80 years of age (Table 1). More than half of the 2010 sample (56%) and a majority of the 2000 sample (71%) had a low education level. Deceased LASA sample members in the 2010 sample were most frequently married (52%), as were members in the 2000 sample (48%). The most commonly reported cause of death was cancer (2010 30%, 2000 25%), followed by heart disease (2010 18%, 2000 17%) and old age (2010 11%, 2000 16%). Furthermore, in the 2010 sample dementia was a significantly more frequent cause of death (7%) compared to the 2000 sample (1%). The 2010 sample reported significantly more symptoms of pain (83% versus 57%) and feelings of anxiety and depression (63% versus 41%) than the 2000 sample. Moreover, all four of these symptoms were more severe in the 2010 sample (mean 2.3-2.8 versus 2.0-2.4). A significantly higher percentage of people in the 2010 sample had problems with incontinence for both urine and faeces, compared to the 2000 sample (28% versus 12%). The 2010 sample was significantly more functionally impaired three months before death (mean at three months = 13.7) compared to the 2000 sample (mean three months = 15.9). At three days before death the mean difference in functional impairment between 2010 and 2000 (8.5 versus 9.6) was not significant.
Received care in the last three months of life

Figure 1 shows that in the 2000 sample significantly more people did not receive any care in the last three months of life (39%), compared to the 2010 sample (12%). In the 2010 sample, significantly more people received formal home care (18% versus 2%) or a combination of formal and informal home care (27% versus 13%). The number of people receiving institutional care remained the same for people in the 2010 sample (36%) as for the 2000 sample (37%).

* Missing observations: less than 5% in the 2000 sample and 6% in the 2010 sample; difference between 2000 sample and 2010 sample is significant (p<0.001) for no care, formal home care and a combination of formal and informal home care.
Table 1 Characteristics of the deceased older people in the 2000 sample and the 2010 sample (rounded weighted %)

<table>
<thead>
<tr>
<th></th>
<th>2000 sample</th>
<th>2010 sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 270</td>
<td>n = 133</td>
</tr>
<tr>
<td><strong>Age (range)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 70</td>
<td>19</td>
<td>19</td>
</tr>
<tr>
<td>70-80</td>
<td>32</td>
<td>32</td>
</tr>
<tr>
<td>&gt; 80</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>51</td>
<td>51</td>
</tr>
<tr>
<td><strong>Education†</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>71</td>
<td>56</td>
</tr>
<tr>
<td>Middle</td>
<td>19</td>
<td>31</td>
</tr>
<tr>
<td>high</td>
<td>10</td>
<td>14</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>48</td>
<td>52</td>
</tr>
<tr>
<td>Widowed</td>
<td>43</td>
<td>40</td>
</tr>
<tr>
<td>Single</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Divorced</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td><strong>Cause of death</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>25</td>
<td>30</td>
</tr>
<tr>
<td>Heart (disease, arteries or attack)</td>
<td>17</td>
<td>18</td>
</tr>
<tr>
<td>Old age</td>
<td>16</td>
<td>11</td>
</tr>
<tr>
<td>Stroke</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>Lung (asthma, CARA, COPD, pneumonia)</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Organs failure</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Dementia</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Other cause of death</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Pain and other symptoms (yes)‡</strong></td>
<td>57†</td>
<td>83†</td>
</tr>
<tr>
<td>Severity (mean (SD))</td>
<td>2.4 (0.6)</td>
<td>2.6 (0.5)</td>
</tr>
<tr>
<td><strong>Shortness of breath (yes)‡</strong></td>
<td>50</td>
<td>54</td>
</tr>
<tr>
<td>Severity (mean (SD))</td>
<td>2.0 (0.8)</td>
<td>2.6 (0.5)</td>
</tr>
<tr>
<td><strong>Fatigue (yes)‡</strong></td>
<td>81</td>
<td>89</td>
</tr>
<tr>
<td>Severity (mean (SD))</td>
<td>2.4 (0.6)</td>
<td>2.8 (0.4)</td>
</tr>
<tr>
<td><strong>Feelings of depression or anxiety (yes)‡</strong></td>
<td>41†</td>
<td>63†</td>
</tr>
<tr>
<td>Severity (mean (SD))</td>
<td>2.3 (0.5)</td>
<td>2.3 (0.5)</td>
</tr>
</tbody>
</table>
End-of-life care and transfers: changes over a decade

Incontinence

<table>
<thead>
<tr>
<th>Incontinence</th>
<th>2010</th>
<th>2000</th>
</tr>
</thead>
<tbody>
<tr>
<td>No incontinence</td>
<td>61</td>
<td>42</td>
</tr>
<tr>
<td>Incontinence for urine</td>
<td>21</td>
<td>25</td>
</tr>
<tr>
<td>Incontinence for faeces</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Incontinence for both urine and faeces</td>
<td>12</td>
<td>28</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Functional ability (mean (SD))</th>
<th>3 months before death</th>
<th>3 days before death</th>
<th>3 months before death</th>
<th>3 days before death</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>15.9 (6.8)</td>
<td>9.6 (7.1)</td>
<td>13.7 (6.6)</td>
<td>8.5 (6.4)</td>
</tr>
</tbody>
</table>

* Missing observations in less than 5% of the total cases for all variables, except for the 2000 sample pain (16%), fatigue (15%), shortness of breath (6%), mood (7%), incontinence (6%), functional ability 3 months (10%) and 3 days (10%) before death and for the 2010 sample pain (38%), fatigue (29%), shortness of breath (11%), mood (37%), incontinence (32%) and functional ability 3 days (16%).

† Difference between 2000 sample and 2010 sample is significant (p < 0.05).

‡ Symptoms present in the last week of life. Severity was measured with 1=not very severe symptoms, 2=relatively severe symptoms and 3=very severe symptoms.

§ Scores range from (5) ‘respondents were unable to perform any of the five activities of daily living’ to (25) ‘respondent was able to perform all five activities with no difficulty’; the five activities concerned ‘go up and down the stairs (15 steps), (un)dress oneself, sit down in and get up from a chair, walk for five minutes outside the house, and use own or public transportation’.

Place of residence, transfers and place of death

Table 2 shows that around two-thirds of the older people in both samples lived in their own home in the last three months of life (2010 65%, 2000 64%). About half of older people were transferred between care settings one or more times in the last three months of life, both in the 2010 sample (47%) and 2000 sample (49%), mostly from home to hospital (2010 28%, 2000 32%). Although two-thirds of the people in the 2010 sample, as in the 2000 sample, lived in their own home during the last three months of life a third died in their own home (34% both years) and a third died in a hospital (2010 29%, 2000 35%).
Table 2  Place of residence, transfers in last three months of life and place of death (rounded weighted %)*

<table>
<thead>
<tr>
<th>Place of residence (at the moment of three months before death)</th>
<th>2000 sample (n = 270)</th>
<th>2010 sample (n = 133)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own home</td>
<td>64</td>
<td>65</td>
</tr>
<tr>
<td>Residential home</td>
<td>19</td>
<td>20</td>
</tr>
<tr>
<td>Nursing home</td>
<td>11</td>
<td>13</td>
</tr>
<tr>
<td>Hospital</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Hospice</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

Transfer(s) last three months of life

<table>
<thead>
<tr>
<th>Types of trajectories last three months of life †</th>
<th>2000 sample (n = 270)</th>
<th>2010 sample (n = 133)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Home &gt; Hospital</td>
<td>32</td>
<td>28</td>
</tr>
<tr>
<td>2. Home &gt; Hospital &gt; Home</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>3. Home &gt; Hosp &gt; Res. with higher level of care</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>4. Place of Res &gt; Res. with higher level of care</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>5. Place of Res &gt; Res. with a lower level of care</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

Place of death

<table>
<thead>
<tr>
<th>Place of death</th>
<th>2000 sample (n = 270)</th>
<th>2010 sample (n = 133)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own home</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Residential home</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>Nursing home</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>Hospital ‡</td>
<td>35</td>
<td>29</td>
</tr>
<tr>
<td>Hospice</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Other (straat, bezoek, zorghostel)§</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

* Missing observations for all variables were less than 5%.
† For type of transfers home refers to own home in 62% (2000 sample) and 59% in the 2010 sample, and to residential home in 19% of the cases (2000 sample) and 18% (2010 sample). Sequence lower to higher care refers to home-residential home-nursing home or hospice-hospital.
‡ Difference between 2000 sample and 2010 sample is significant (p < 0.05).

Association with type of care and dying in hospital

The bivariate analyses showed that compared to people in the 2000 sample the people in the 2010 sample were more likely to receive formal home care (OR 6.6(3.7-12)) and institutional care (OR 2.2(1.3-3.9)) than no or informal care (Table 3). Multivariate analyses examined whether these associations would remain when patient characteristics were controlled for (Table 3). Year of measurement remained significantly associated with type of care (formal home care OR 6.9(3.3-14.4), institutional care OR 2.5(1.2-5.3)). In addition, other variables proved significant in the multivariate analyses. Females and people over 80 were more likely to receive formal home care (men OR 0.74(0.36-1.5) and age>80 OR 3.7(1.4-9.7))

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and especially institutional care (men OR 0.34(0.17-0.68) and age>80 OR 11.6(3.4-39.7)),
compared to no or informal home care. Furthermore, people with higher functional abilities
were less likely to receive formal home care (OR 0.84(0.79-0.84)) or institutional care (OR
0.76(0.71-0.81)), compared to no or informal care.

Concerning dying in hospital, only type of care was significant in the multivariate analyses:
people receiving informal home care (OR 2.3(1.1-4.6)), were more likely to die in a hospital
(Table 3).

Table 3 Factors associated with type of care arrangement in the last three months of life and dying in
hospital (OR and 95% confidence intervals) *

| Care arrangements (multinomial regression analysis, OR and 95% confidence intervals)† |
|---------------------------------|----------------|----------------|
|                                | No or only Informal home care | Formal home care | Institutional care |
| Age                             | OR(CI) | OR(CI) | OR(CI) |
| (<70)                           | 1.0    | 1.0    | 1.0    |
| (70-80)                         | 1.0    | 1.6 (0.56-4.9) | 4.7 (1.3-17.5) |
| (>80)                           | 1.0    | 3.7 (1.4-9.7)  | 11.6 (3.4-39.7) |
| Gender (male)                   | 1.0    | 0.74 (0.36-1.5) | 0.34 (0.17-0.68) |
| Functional ability (metric)‡   | 1.0    | 0.84 (0.79-0.89) | 0.76 (0.71-0.81) |
| Year (2010)                     | 1.0    | 6.9 (3.3-14.4)  | 2.5 (1.2-5.3) |

Dying in hospital (multivariate logistic regression analysis, OR and 95% confidence intervals)§

<table>
<thead>
<tr>
<th>Hospitalization until death</th>
<th>Hospitalization until death</th>
</tr>
</thead>
<tbody>
<tr>
<td>OR(CI)</td>
<td></td>
</tr>
<tr>
<td>n = 132</td>
<td></td>
</tr>
<tr>
<td>Informal home care</td>
<td>2.3 (1.1-4.6)</td>
</tr>
<tr>
<td>Formal home care</td>
<td>1.5 (0.86-2.9)</td>
</tr>
<tr>
<td>Institutional care (reference)</td>
<td>1.0</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>(&lt;70)</td>
<td>1.0</td>
</tr>
<tr>
<td>(70-80)</td>
<td>1.4 (0.67-2.9)</td>
</tr>
<tr>
<td>(&gt;80)</td>
<td>1.4 (0.69-2.8)</td>
</tr>
<tr>
<td>Gender (male)</td>
<td>0.77 (0.47-1.2)</td>
</tr>
<tr>
<td>Year (2010)</td>
<td>1.0 (0.59-1.7)</td>
</tr>
</tbody>
</table>

* Year of measurement, age and sex were forced in the logistic model.
† Variables that did not remain significant in the multinomial multivariate analysis: education and marital status.
‡ Scores range from (5) ‘respondents were unable to perform any of the five activities of daily living’
to (25) ‘respondent was able to perform all five activities with no difficulty’.
§ Reference no hospitalisation until death (n=305); variables that did not remain significant in the
multivariate logistic regression: age, gender, year of measurement, education, marital status, cancer
(or other disease) and functional ability.
DISCUSSION

This study compares the care received by older people during the last three months of their life in the year 2000 and 2010 by a replication study. Data were derived from the LASA cohort, which is based on a nationally representative sample of older adults aged 55-85 years, stratified by age and gender and reflecting national distribution of urbanization and population density. The study revealed that people who died between 2005-2009 had a significant increase in functional disabilities, compared to people who died between 1995-1999. Also in ten years time, the care received in the last three months of life seems to have changed to constitute significantly more formal home care, or a combination of formal and informal home care in the 2010 sample. Furthermore, compared to people who received no or only informal home care, people were more likely to receive formal home or institutional care if they were in the 2010 sample, female, over 80 years, or had a lower functional ability. Half the older people moved one or multiple times to another care setting in the last three months of life in both sample years. People living in an institution had a reduced chance of hospitalization until death regardless of sample year. Place of death did not change in ten years.

Strengths and limitations
The strength of this study is that the data are derived from a representative sample of the Dutch older population. Furthermore, a strength is the replication of the similar sampling method and questions over ten years to monitor changes in care. The study is limited however by the difference in the method of examining of the questions, with an interview in 2000 and a self-administered questionnaire in 2010. Another limitation of this study is a potential bias in the data due to retrospective reporting: the LASA sample members deceased a half year up to maximum three and a half years before the proxies entered the study and there might be recall bias. However, it is likely that proxies remember circumstances around the death of a relative. Literature confirms that proxies give accurate information, especially when it concerns more factual information such as chronic diseases and service provision of a deceased relative. Reporting of less factual information can be less accurate. Previous research on the agreement in reporting personal care abilities between older female patients in the UK and USA and their proxies, underlined that proxies were reliable in reporting abilities by proxies, but also reported that proxies were likely to report more disabilities. Furthermore, a tendency to produce better agreement was suggested for proxies with a more distant relationship and contact. It is not known whether this also hold for recalling personal care abilities a shorter and longer period after a person’s death.
The reduced functional ability of older people in the 2010 sample is in line with the predicted ageing of the population, and the assumption that people live longer with chronic diseases \(^1,2,4,6,7,36-38\). This study confirmed the increase in formal home care and the remaining high use of institutional care, and it’s relation to age and functional ability that has been reported before \(^9,10,39-41\). A novel finding is the influence of time on care received, independent of age, gender, functional status, marital status and educational level. Several factors can contribute to this influence. First, people in the 2010 sample may have received more formal home care and institutional care compared to people in the 2000 sample, because the availability of informal caregivers has decreased. Family structures are changing over time and this may have influenced the time informal caregivers can spend on taking care of their loved ones. This may be due to work obligations, children living far away and a higher number of women working \(^42,43\). Second, it is also possible that older people now prefer formal home care over informal care, as they may prefer to maintain their autonomy and not be dependent on family \(^42\). Since older people in the 2010 sample had more severe symptoms and disabilities, a third possibility is that they may have needed more care than informal caregivers are able to give. Finally, the increased availability of especially formal home care services for palliative care in the Netherlands in the last decade might have been influential \(^27,37,44\).

Despite increases in formal home care, the percentage of elders transferred to a care setting in the last 3 months of life did not change in ten years: half the people in both the 2010 and 2000 sample experienced one or more transfers to different care settings. Transfers in last phase of life are argued to reduce the continuity of care and perceived quality of life \(^26,45\) and are therefore preferably prevented. However, some transfers are inevitable from a medical perspective and due to conditions of progressive frailty \(^36,46\). In addition, some older people prefer to be transferred to a care service in order to receive professional care \(^47\).

Despite the increased emphasis in policy to support home care \(^5-11,27\), and our finding that formal home care has increased, the percentage of home deaths did not increase in ten years (i.e. 1 out of 3 in both samples). Besides that, a small but significant decrease in hospital deaths was found (35%-29%). Keeping in mind the decreased functional ability of older people in the last phase of life in the last decade, it is possible that the increased availability of palliative home care did prevent a decrease in home deaths.

The present study indicates that people receiving informal home care are more likely to be hospitalized until death. For this group, a sudden decline in the condition of these people might have led to hospital admission for professional treatment and symptom control. Alternatively, treatment in hospital may have been assessed as potential life prolonging or
lifesaving, but despite this assessment they died in the hospital. Another possibility is that health care professionals may not have recognized that these people were already in their palliative phase.

People who receive home care are more likely to die in hospital, compared to people receiving institutional care. Probably the latter group already receives care within their nursing or residential home, and they therefore do not have to change from their (already medical) environment for symptom control or life-prolonging treatments 48,49.

In summary, two scenarios of care in the last three months of life seem to arise from the data: staying at home as long as possible with a higher chance of dying in hospital, or reducing the chance of dying in hospital by living in a residential or nursing home. The health-care professionals could take this into account when discussing with patients in light of advance care planning: older people might prefer staying at home, accepting the higher chance of dying in hospital, or they might prefer timely transfer to a residential or nursing home which may avoid hospital death. Since in the last decade there was a decrease in functional ability of older people, no decrease in the number of home deaths, and an increase in the availability of palliative home care, making optimal use of palliative home care seems crucial when people do want to stay at home.

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