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Transitions between care settings at the end of life in The Netherlands: results from a nationwide study

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ABSTRACT

Multiple transitions between care settings in the last phase of life could jeopardize continuity of care and overall end-oflife patient care. Using a mortality follow-back study, we examined the nature and prevalence of transitions between Dutch care settings in the last 3 months of life, and identified potential characteristics associated with them. During the 2-year study period, 690 registered patients died 'totally expectedly and non-suddenly'. These made 709 transitions in the last 3 months, which involved a hospital two times out of three, and covered 43 distinct care trajectories. The most frequent trajectory was home-to-hospital (48%). Forty-six percent experienced one or more transitions in their last month of life. Male gender, multi-morbidities, and absence of GP awareness of a patient's wish for place of death were associated with having a transition in the last 30 days of life; age of ≤85 years, having an infection and the absence of a palliative-centred treatment goal were associated with terminal hospitalization for ≥7 days. Although the majority of the 'totally expected and non-sudden' deaths occurred at home, transitions to hospitals were relatively frequent. To minimize abrupt or frequent transitions just before death, timely recognition of the palliative phase of dying is important.

INTRODUCTION

Care setting transitions at the end of life can be burdensome for those concerned.1–4 Arguably, such transitions pose a challenge to the continuity of patient care.5 With rising life expectancy in developed countries, significant numbers of deaths will follow ageing and multiple chronic illnesses.1,6 The protracted nature of these non-acute deaths often warrants transitions between settings, 2,3,7 since different illness trajectories suggest different care needs.8 The underlying aim of palliative care is to ensure the best possible quality of life for the entire duration of an illness.1,9 To achieve this, patients require optimal comfort and relative stability,1,10 devoid of illplanned transitions.2,4,7 There is a potential relationship between end-of-life transitions and patient safety, comfort, quality of life and general well being.10,11 Moreover, transitions to hospitals and other acute settings at the end of life tend to provide more aggressive and potentially futile treatments,2,4,11 at the expense of enhancing continuity.12,13 From a care perspective, some transitions will be inevitable.2,11,14 In the Netherlands, the tradition of openness and

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candour makes the expression of preferences for place of care commonplace.15 Dutch General Practitioners (GPs) provide continuity of care between settings at the end of life,2,12,13 but in common with other physicians may be unable to identify the terminal phase in all dying patients.16 In addition, they oversee terminal care in residential homes and at home,17 the preferred place of death for many.18 However, data monitoring from the general population on the epidemiology of transitions at the end of life, rather than individual evaluation of the care of dying patients, is scarce.2,18 Past studies on end-of-life transitions have focussed on characteristics of dying in certain settings, 17,18 on transitions within distinct patient or care groups,3,10,17 or on transitions to specific settings.19,20 The first population-based study on transitions between care settings (Senti-MELC) was performed in Belgium.7 Using a similar methodology, this study seeks to address the following four research questions: 1. How often are patients transferred between care settings in the final 3 months of life? 2. Which distinct care setting trajectories can be identified in the final 3 months of life? 3. Where are these patients cared for in the last 90 days of life? 4. What patient, disease and healthcare characteristics are associated with care setting transitions in the last month (30 days) of life, and with terminal hospitalization throughout the last week (7 days) of life?

METHODS

Study design and population

This study, the Senti-Monitoring End-of-Life Care (SENTI-MELC) is a mortality follow-back study which seeks to monitor the quality of care provided via GPs to a general population of end-of-life patients in the Netherlands. This method was first used and reported in Belgium.7,19,21 Between 2005 and 2006, appropriate patient data were collected via the nationwide Dutch Sentinel Network of GPs, an existing health surveillance instrument.22,23 This network consists of 45 general practices (65–70GPs) and covers approximately 1% of the entire 16 million registered patient population in the Netherlands.23 The data collection process was supervised by the Netherlands Institute of Health Services Research (NIVEL). With the exception of nursing home deaths, our sample was representative nationwide; gender and age were comparable per setting to corresponding mortality rates per setting in the Netherlands.24

Procedure

Within 1 week of reporting a patient's death, participating sentinel GPs were asked to fill in a registration form surveying information regarding the care the deceased received in the last 3 months of life. In order to clearly identify those patients who were not eligible to receive palliative care in their last days, GPs were asked if the death in question had been both 'sudden and totally unexpected'.

Also, patients ≤1 year old were not registered so as to exclude deaths from congenital problems. On completion, the registration forms were returned to NIVEL where they were scrutinized for missing data and errors, duplicated and then sent to the researchers for analysis.

Measurement instrument

Following an exhaustive literature review of themes relevant to end-of-life care, and review by a multidisciplinary team of researchers, questions were developed, reviewed and adapted. The resulting registration form comprised 15 items (one A4 page) which included multiple-choice and open-response questions on the following: patient characteristics; cause of and pre≥ferred place of death; care characteristics including locations of care in the last 3 months of life; GP awareness of preferred place of death; involvement of specialist (multidisciplinary) palliative care services; the main goal of patient's treatment (curative/life prolonging/palliative); the main focus of care (physical/psychosocial/spiritual); the place of care (3 months to weeks before death); and the actual place of death. Next the GPs were asked to provide the settings in which the patients had received care during the last 3 months of life, and the number of days spent per transition.

Definitions

A transition is a change in setting or location of care

A trajectory is the pathway of care settings a patient lived in, during the last 3 months of life

Terminal hospitalization refers to hospitalization until death

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Place of death in the Dutch context:

Settings for receiving end-of-life care and for dying in the Netherlands can be classified into two broad categories:

- Regular settings (homes and care homes)
- Specialized settings (nursing homes, palliative care units including hospices, hospitals)

These settings offer a variety of possibilities or care packages. Care homes are residential homes for the elderly, and provide basic support usually through informal caregivers. Inhabitants of care homes, like those at home, remain under the care of their GPs.16 Nursing homes have their own specialist physicians who take over patient care from GPs following transfer of the patient. This implies that care trajectories involving nursing homes are usually outside the purview of GPs.16,25 Palliative care units and hospices provide patients with specialized end-of-life care.26 They operate exclusively, or sometimes as an extension of hospitals, care and nursing homes.

[TABLE 1]

Statistical analyses

From the 690 non-sudden deaths registered via the sentinel GP network, we calculated the frequency of transitions and charted all distinct care trajectories per place of death in the last 3 months of life. We then used regression analyses to examine the characteristics which were associated with having a transition in the last 30 days of life or being hospitalized for all of the last 7 days of life.

Multivariate analyses followed the univariate binary regression whenever the patient or care characteristics were found to be significantly associated with ≥1 transition.

All variables having significant relationships were included in a stepwise backward logistic regression in order to make a predictive model. Results were tested using the Wald chi-square test at one degree of freedom and were considered significant if the p-value was <0.05.

Similar analyses were repeated to identify characteristics associated with having a terminal hospital admission of at least 7 days. SPSS for Windows version 15.0 was used for all our analyses.

Ethical consideration

An approval from the Dutch Ethical Review Board was not required for this study because the data were collected post-mortem. However, strict patient and physician anonymity was preserved throughout the registration and data entry process as required.

RESULTS

Study population and frequency of transitions in the last 3 months of life

Between 1 January 2005 and 31 December 2006, 690 ‘totally expected and non-sudden deaths’ were registered via the Dutch Sentinel network of GPs. Thirty-five percent of the patients were aged 85 years or more, 52% were male, 52% had no regular partner or spouse, 25% had financial resources estimated as ‘below average’ and 42% died of cancer. Most of the patients (67%) experienced one or more transitions in the last 3 months, 46% in the last month, and 19% in the last week of life (Table 1). Altogether, a total of 709 transitions were made within the last 3 months, producing 43 distinct care trajectories, 67% of which involved a hospital at some point in time.

Distinct care setting trajectories in the last 3 months of life

Forty-three distinct care setting trajectories (in Figure 1) converged to five different settings in the Netherlands: 19, 8, 5, 1 and 10 trajectories for patients who had died at home, care home, nursing home, palliative unit/hospice, and hospital, respectively. Of the patients at home 3 months prior to death, 36% experienced no transition, 36% were transferred to a hospital and died there, and 9% were transferred from home to hospital and back home again. With regard to care homes, 73% of the patients had no transition, 17% were transferred once to a hospital where they died, and 5% were transferred via the hospital to a home, care home or nursing home.

Overall, trajectories from home to hospital (48%), home to hospital to home (12%), care home to hospital (5%), and home to hospital to nursing home (5%) were most frequent. There was no transition from a hospice or palliative care setting to a hospital in the last 3 months of life.

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The places of care in the last 3 months of life

Figure 2 shows the number of patients staying in a particular setting on a day-by-day sequence, per three time-intervals within the last 90 days of life. Within the 60–90-day interval prior to death, patient numbers remained fairly similar per setting. In the 30–60-day interval prior to death, the proportion of patients on hospital admission increased gradually, while the proportion at home reduced likewise. [figure 1] [figure 2] In the last 30-day interval, there was a much steeper increase and drop in the proportion of patients at home and in hospital, respectively. Proportions of patients in nursing homes and palliative care units (or hospices) also increased somewhat. The proportion of patients in care homes remained relatively constant throughout the three time intervals within the patients' last 3-month period.

Characteristics associated with ≥1 transition in the last 30 days, and terminal hospitalization throughout the last 7 days of life

Within the last month of life, female patients, patients aged below 65 and those above 84 years, those with single morbidities, and those suffering from acute respiratory disorders and infections such as pneumonia were less likely to be transferred in the last month of life. Also, the patients whose GPs were aware of their 'place of death' wish and whose care in the last phase of life was primarily 'palliative' were less likely to be transferred (Table 1).

With respect to terminal hospitalization in the last 7 days of life, patients older than 84, those without infections, those whose GPs were aware of their 'place of death' wish, and those with a 'palliative care' treatment goal were less likely to be hospitalized for a minimum of 7 days until death, than all others (Table 2).

DISCUSSION

We examined the pattern of end-of-life transitions between different care settings over a 2-year period in the Netherlands. From the 690 patients whose deaths were 'totally expected and non-sudden', we identified 43 distinct care trajectories and 709 transitions (67% involving a hospital) in the last 3 months of life. The most frequent trajectory was home-to-hospital (48%).

Forty-six percent of the cohort experienced ≥1 transition in their last month of life. Being male, having multiple morbidities and an absence of GP awareness of a patient's preferred place of death were associated with having a transition in the last 30 days of life, whereas being aged ≤85 years, having an infection and no palliative- centred treatment goal were associated with terminal hospitalization for ≥7 days.

This is the first nationwide study that attempts to monitor and estimate the number of transitions between [table 2] care settings at the end of life in the Netherlands. Rather than evaluate individual patient care, we examined a general patient population of all those who could potentially benefit from planned terminal care, or at least palliative care – which comprised more than just cancer patients.1,3,12 The ultimate goal is to use the information generated for organizing health care, particularly for older people. Adequate knowledge of transition trends could dictate areas where potential challenges lie, in terms of planning.

The quality of our reporting was enhanced by the participation of trained sentinel GPs,21,23 who play a gate-keeper function to the health care system in the Netherlands.23 Their function as patient-proxies, however, may have constituted a limitation, perhaps resulting in self-reporting and information biases.14,21 Also, it is possible that some GPs missed out on some transitions in the course of the registration. Nevertheless, the chance of GPs missing a transition would be higher for patients in nursing homes than for those residing at home or in care homes.

In comparison with the Belgian SENTI-MELC study on transitions,7 patient characteristics were quite similar; patients >85 years (35% : 32%), male gender (52% : 49%) and deaths from cancer (42% : 41%), for the Dutch and Belgian studies, respectively.

At least one transition was experienced by 78% of patients residing at home and 92% of patients residing in care homes, in contrast to 73% and 36%, respectively, in Belgium. The most frequent trajectory in the Netherlands (as in Belgium) was from home-to-hospital (36% versus 40%). The Belgian cohort experienced no transition at all in more instances than the Dutch (38% versus 33%), although the Belgian cohort had many more hospitalized versus home patients at death (40% to 26%) than the Dutch (34% to 37%). However, the variation in transition trends observed cannot be interpreted in isolation, despite some inherent similarities in both health care systems.7,17,27 The majority of the transitions we reported took patients away from, rather than to, their homes or usual place of residence. This is ironical because the

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'home' is often considered to be the most preferred place of death,2,17,18 and dying in one's preferred place could be related to the quality of dying and terminal care.2,11,28 Comparatively, transitions from care homes were fewer than those from homes, even though care in both settings is routinely managed by the same GPs. This is perhaps because care home residents are predominantly elderly, who often demand less aggressive treatment.29 It is understandable also that based on age, death would more expected and discussed in care homes.14,18,30 From our results, those who were not transferred in their last month of life were more frequently women, were >85 years of age, and had no regular partners. These characteristics generally match those of care home inhabitants, and are in consonance with findings from a Canadian study.10 Overall, a small percentage of transitions involved a palliative care setting or hospice. The pattern observed may be unique to the Dutch system of care which has specialist physician-run nursing homes.25 However, late decisions for referral to hospices could debar terminally ill patients from the various kinds of specialized palliative care initiatives that such units provide. Unlike findings from Belgium and Japan, our study shows that no patient was transferred away from a hospice or palliative care setting to a hospital.7,30 This may have been due to the fact that these settings are better equipped to handle medical emergencies.17 We recognize that all transitions to hospitals are not in themselves bad or unnecessary. Gott et al.29 demonstrated that many older people prefer to be cared for away from home at the end of life. Also, it is clear that some of the medical conditions which led to death in the patients who were hospitalized might have required the kind of care hospitals are best equipped to provide (exploration of this was outside the scope of our study), i.e. an acute episode of infection could warrant hospitalization.

These points notwithstanding, definite attempts should be made to factor transitions into individual patient management, with increased GP awareness of patient and family preferences and timely communication of the care goals, including those outside the realm of immediate care. Our findings – the GP being aware of a patient's preferred place of death and the main treatment goal being palliative care – point in this direction.

In conclusion, our data show that most 'non-sudden and totally expected' deaths in the Netherlands take place at home, and that transitions to hospitals are relatively frequent. Two-thirds of these patients experienced transitions between care settings in the last 3 months of life, while 20% were transferred between care settings in the last week of life. The frequency of transitions on a population level increased markedly in the last month of life, possibly due to changes in the clinical situation of the patients as death approached. In Belgium, unlike the Netherlands, the percentage number of patients in hospital exceeds those at home in the last 10 days of life, probably as a result of country-specific reasons. In order to minimize transition-related burdens to patients and carers, even in the most justifiable of cases, anticipation and timely recognition of the palliative phase is advised. Furthermore, integration of palliative care into general end-of-life care may accrue long-term cost benefits.31

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The corresponding author had full access to all the data in the study and has the final responsibility for the decision to submit for publication.

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TABLE 1

Table 1. Total number of care setting transitions made during the last 3 months of life ($n = 690$[a])

	Last 3 months of life		Last month of life		Last 7 days of life	
Number of transitions[b]	*n*	Column % (95% CI)[c]	*n*	Column % (95% CI)[c]	*n*	Column % (95% CI)[c]
None	224	32.8 (29.3–36.3)	371	54.0 (50.3–57.7)	551	80.2 (77.2–83.2)
One	258	38.4 (34.8–42.0)	254	37.0 (33.4–40.6)	132	19.2 (16.3–22.2)
Two	143	20.7 (17.7–23.7)	57	8.3 (6.3–10.6)	4	0.6 (0.2–1.5)
Three	55	8.1 (6.2–10.4)	5	0.7 (0.2–1.7)	0	–

a. Transitions missing for 3 cases. b. A maximum of 3 transitions were recorded per case. c. Multinomial confidence interval (95%): exact method.

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FIGURE 1

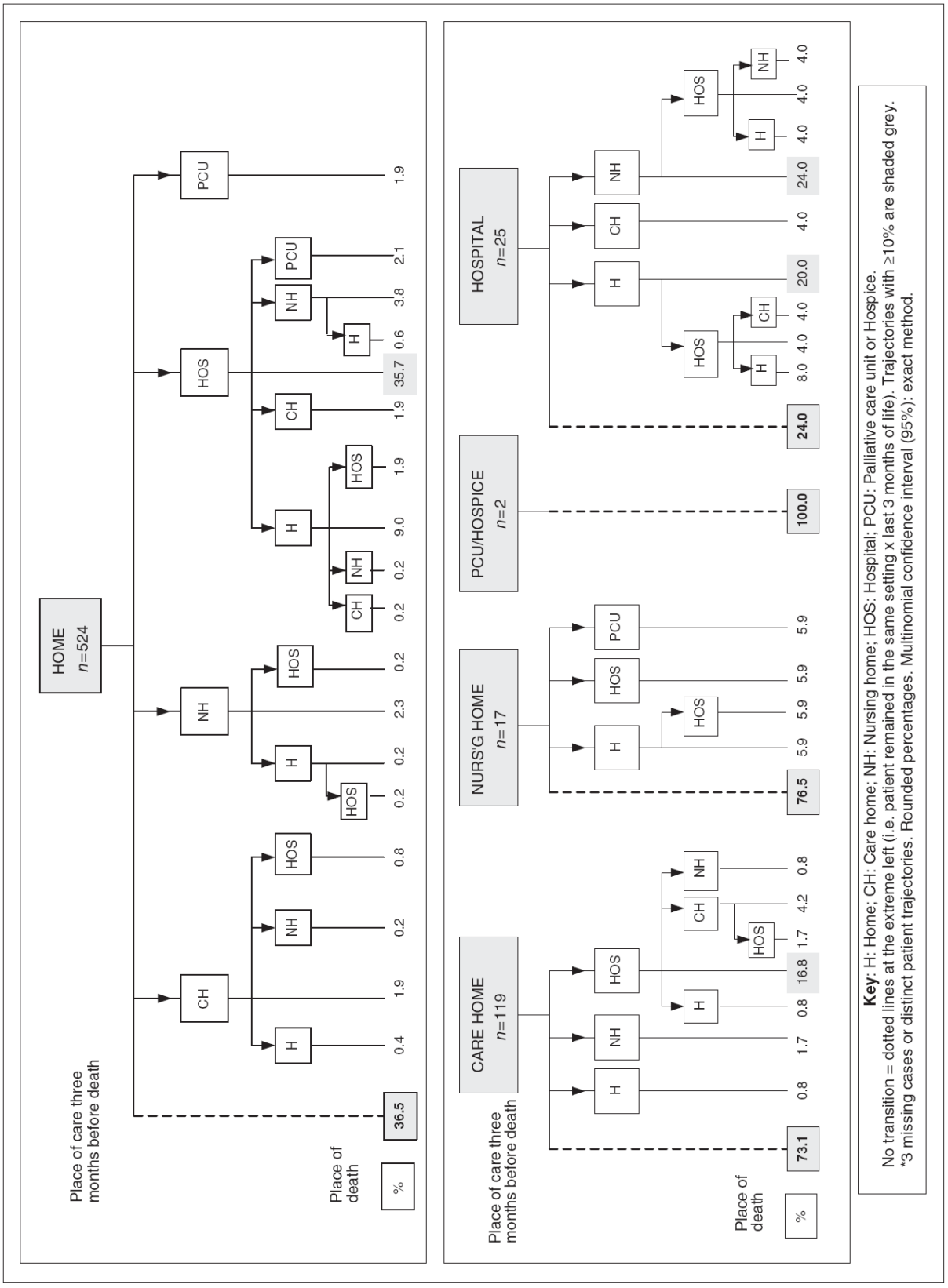

Figure 1. Distinct care setting trajectories in the last 3 months of life ($n = 690^{*}$).

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FIGURE 2

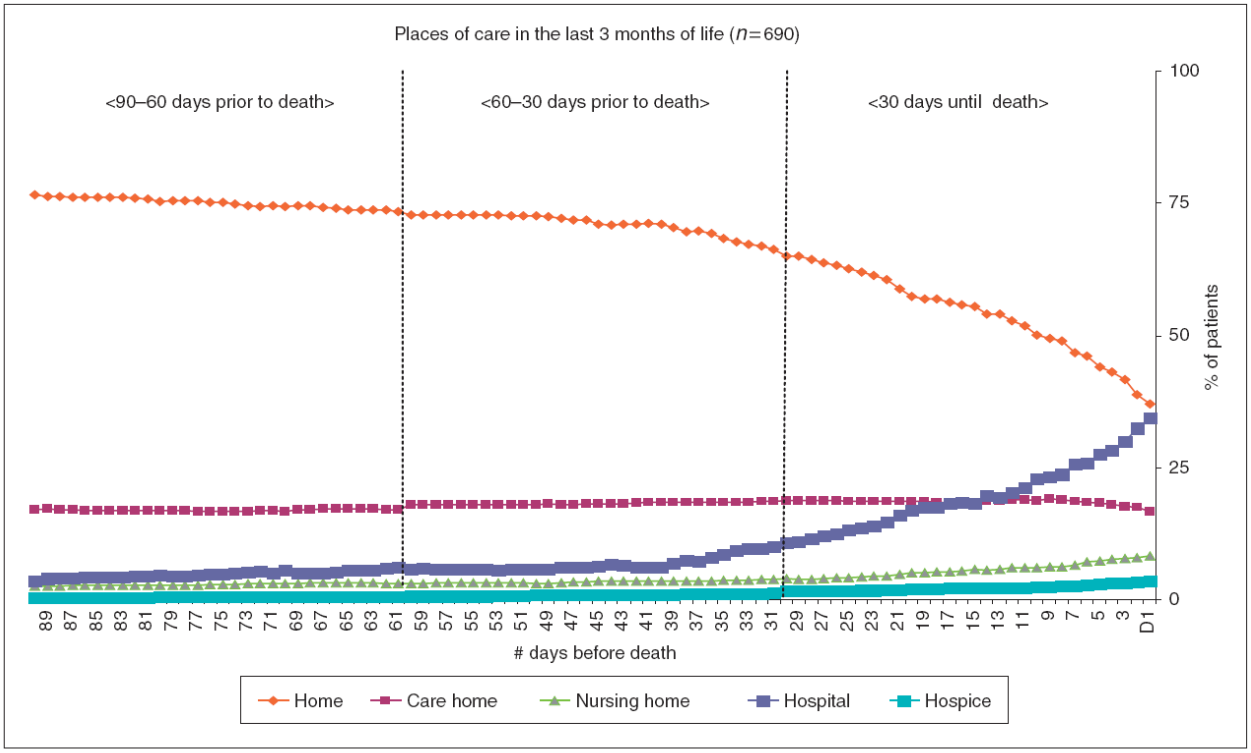

Figure 2. Transition between care settings in the last 3 months of life ($n = 690$*).
The *X*-axis represents the number of days prior to death.
The *Y*-axis represents the percentage of patients in a particular setting.
Care trajectories were missing for three cases. Rounded percentages.
Multinomial confidence interval (95%): exact method.
Note that the places of care from 30 days prior to death demonstrate a steep transition gradient in the last few weeks of life.

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TABLE 2

Table 2. Characteristics associated with 'one or more transition' in the last 30 days of life ($n = 690$*) and with staying in a hospital for ALL the last 7 days of life ($n = 690$)

	Patients had a transition between care settings in last 30 days of life[a] Row %			Patients who spent their last 7 days on a hospital admission[a] Row %		
Patient characteristics:	No $n = 371$	Yes $n = 316$	Odds ratio[b]	No $n = 540$	Yes $n = 147$	Odds ratio[b]
Age						
– 1–64 years	59	41	1.5 (0.8–2.7)	76	24	**3.2 (1.6–6.5)**
– 65–84 years	48	52	**1.7 (1.1–2.7)**	75	25	**2.1 (1.2–3.6)**
– 85–104 years	62	38	1.0	85	15	1.0
Gender						
– Male	50	50	**1.9 (1.2–2.9)**	77	23	[c]
– Female	60	40	1.0	82	18	
Had a regular partner						
– Yes	52	48	[c]	77	23	[c]
– No	56	44		81	19	
Financial resource						
– Below average	52	48	[c]	82	18	[c]
– Average	54	46		77	23	
– Above average	59	41		81	19	
Disease entities registered by GP:						
Cancer						
– No	52	48	[c]	76	24	[c]
– Yes	57	43		82	18	
Heart disease						
– No	57	43	[c]	80	20	[c]
– Yes	50	50		77	23	
Respiratory disorders						
– No	56	44	[d]	79	21	[c]
– Yes	37	63		72	28	
Infection (pneumonia, sepsis)						
– No	57	43	[d]	81	19	1.0
– Yes	45	55		68	32	**2.1 (1.3–3.6)**
Multiple morbidities						
– No	61	39	1.0	82	18	[d]
– Yes	42	58	**1.7 (1.1–2.6)**	71	29	
Care characteristics:						
GP awareness of 'place of death' wish						
– No	33	67	**4.1 (2.7–6.3)**	62	38	**6.6 (4.0–11.1)**
– Yes	72	28	1.0	93	7	1.0
Main 'care goal' 30 days before death						
– Curative	32	68	**2.8 (1.5–5.0)**	63	37	**2.1 (1.1–3.8)**
– Life prolonging	34	66	**2.8 (1.6–4.9)**	66	34	**2.0 (1.2–3.6)**
– Palliative	66	34	1.0	86	14	1.0
Main 'care content' 30 days before death						
– Physical	48	52	[d]	78	22	[c]
– Psychosocial	61	39		84	16	
– Spiritual	53	47		76	24	

(continued)

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