

Hospice assist at home: does the integration of hospice care in primary healthcare support patients to die in their preferred location – A retrospective cross-sectional evaluation study

Palliative Medicine

1–7

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DOI: 10.1177/0269216315626353

pmj.sagepub.com



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Abstract

Background: A majority of patients prefer to die at home. Specialist palliative care aims to improve quality of life. Hospice assist at home is a Dutch model of general/specialised palliative care within primary care, collaboratively built by general practitioners and a hospice.

Aim: The aims of this study are to explore whether hospice assist at home service enables patients at home to express end-of-life preferences and die in their preferred location. In addition, this study provides insight into symptom burden, stability and early referral.

Design: A retrospective cross-sectional evaluation study was performed (December 2014–March 2015), using hospice assist at home patient records and documentation. Primary outcome includes congruence between preferred and actual place of death. Secondary outcomes include symptom burden, (in)stability and early identification.

Setting/participants: Between June 2012 and December 2014, 130 hospice assist at home patients, living at home with a life expectancy < 1 year, were enrolled. Hospice assist at home, a collaboration between general practitioners, district nurses, trained volunteers and a hospice team, facilitates (1) general practitioner–initiated consultation by Nurse Consultant Hospice, (2) fortnightly interdisciplinary consultations and (3) 24/7 hospice backup for patients, caregivers and professionals.

Results: A total of 130 patients (62 (48%) men; mean age, 72 years) were enrolled, of whom 107/130 (82%) died and 5 dropped out. Preferred place of death was known for 101/107 (94%) patients of whom 91% patients died at their preferred place of death.

Conclusion: Hospice assist at home service supports patients to die in their preferred place of death. Shared responsibility of proactive care in primary care collaboration enabled patients to express preferences. Hospice care should focus on local teamwork, to contribute to shared responsibilities in providing optimal palliative care.

Keywords

Palliative care, hospice care, general practice, service integration, primary health care, patient preference

What is already known about the topic?

- Patients living at home are less likely to die in their preferred location of death.
- Specialist palliative care services contribute to dying in the preferred location.
- Patients with an expressed end-of-life preference are more likely to die at the preferred location.

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What this paper adds?

- Hospice assist at home (HaHo) provides a framework for the integration of general and specialist palliative care.
- A total of 94% of HaHo patients expressed their preferences during their illness trajectory.
- A total of 91% of patients with an expressed preference died at their preferred place of death.

Implications for practice, theory or policy

- HaHo provides a framework to integrate general and specialist palliative care, adapted to the characteristics of the local healthcare system.
- The early identification of all patients with possible palliative care needs could improve by a systematical assessment of patients with possible palliative care needs, using the 'surprise question'.
- Specialist hospice facilities should conscientiously take a role in optimising the collaboration with local primary care teams.

Introduction

In 2013, 141,000 people died in the Netherlands, of whom 69%–81% needed palliative care, which means that approximately 105,000 patients could have benefitted from palliative care.¹ The majority of patients prefer to live and die at home when faced with an incurable disease.^{2–4} However, in the Netherlands, only 29%–62% of patients who died between 2009 and 2012 were able to die at home.⁵

Palliative care aims to optimise the quality of life of patients with a life-limiting illness and their families by providing relief and prevent suffering caused by physical, psychological, social or spiritual problems.⁶ A multidisciplinary team approach of collaboration and consultation between professionals might be a precondition to provide optimal palliative care.⁷

In the Netherlands, palliative care is provided in all healthcare settings (Figure 1). Since most patients prefer to be cared for and die at home, palliative care is most often provided by general practitioners (GPs) and district nurses (DNs). Multidisciplinary care is the norm in inpatient settings; however in primary care, there are less opportunities for similar models of collaboration. This stems from a lack of natural face to face contacts between healthcare providers, a variety of healthcare providers and competing healthcare organisations. All could negatively influence the quality of palliative care to individual patients in the community.

Worldwide, two levels of palliative care are distinguished. (1) General palliative care – a basic level of palliative care provided by all professionals who are confronted with patients with incurable diseases. (2) Specialist palliative care – an advanced level of palliative care by specialist healthcare professionals and services, specifically focused on providing palliative care during the continuum.⁸

Hospice care is specialist palliative care, providing multidimensional care by a multidisciplinary team of

formal and informal caregivers. Hospice care in the Netherlands is mainly traditional 24/7 inpatient services. Outpatient hospice services are currently developing. Integration of hospice care services and general practice is not yet established. A tailor-made integration of general and specialist palliative care could ameliorate the quality of palliative care for patients and their caregivers at home and enable patients to die at their preferred location.^{9,10}

In 2012, a collaborative team of GPs and a local hospice identified a lack of quality in palliative care for patients at home. The initial problem analysis identified four challenges for improvement: (1) individual knowledge and skills, (2) coordination of care and treatment, (3) out of hours continuity of care for patients, families and healthcare professionals and (4) interdisciplinary communication. With the development of a local palliative care service 'Hospice assist at Home' (HaHo), three interventions were implemented: (1) GP requested specialist home site consultation by a Hospice Nurse Consultant (HNC), (2) set up of a structure for multidisciplinary consultation once a fortnight and (3) 24/7 hospice care backup for patients/families and healthcare professionals. One healthcare professional was primarily responsible for coordination, based on the patients' preferences.

The aim of the HaHo service is to empower patients and caregivers in expressing wishes and priorities by active support in the palliative phase. The aim of this evaluation study was to investigate whether amelioration of the quality of palliative care at home enables patients to (1) express end-of-life preferences and (2) die at their preferred location. This study provides insight into (1) symptom burden, (2) (in)stability and (3) early identification of patients at home.

The ultimate goal of the HaHo service is to provide optimal palliative care to patients and caregivers at home through the integration of general and specialist palliative care within the local healthcare system.

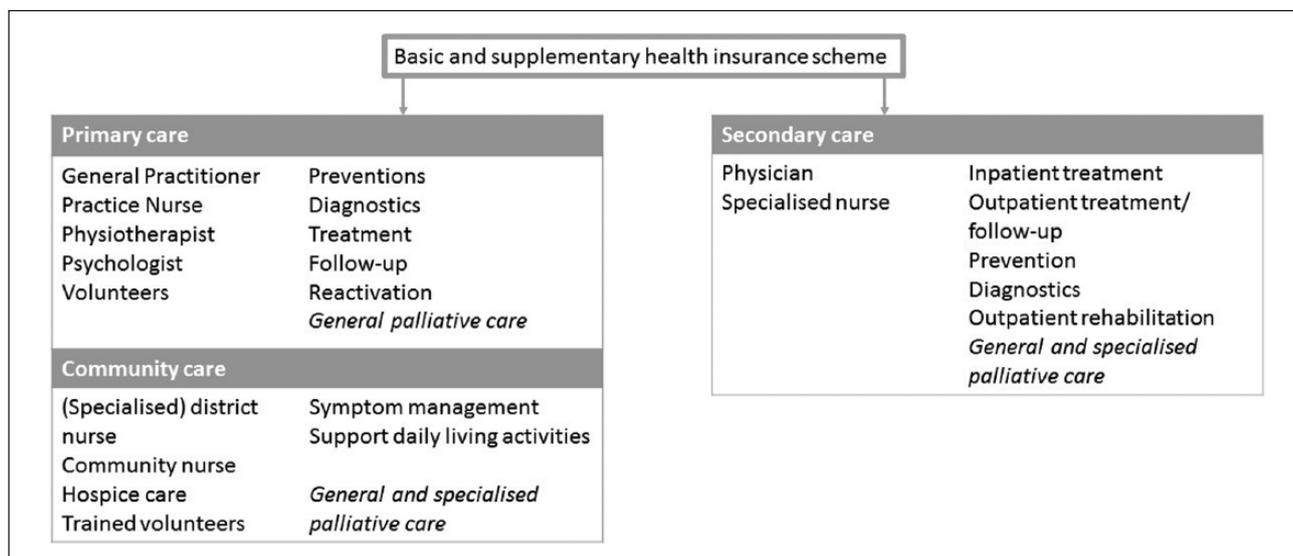


Figure 1. Palliative care healthcare system, the Netherlands.

Methods

Design

A retrospective descriptive cross-sectional study was performed from December 2014 to March 2015. Data were collected prospectively during HaHo involvement for daily care and research purposes.

Setting and population

This study was performed in the community with local caregivers and a hospice facility in the centre of the Netherlands. Patients living at home, with a life expectancy of less than 1 year, were referred to the HaHo service by their GP or DN. The patients' life expectancy was estimated by the GP, using the 'surprise' question: 'Would I be surprised if this patient died in the next year?'¹¹⁻¹³ All patients referred to HaHo from June 2012 to December 2014 were enrolled in the study from referral to death or until the end of the study.

Patient anonymity and ethics approval

Patients referred to HaHo were informed by their HaHo coordinator about the study and the ability to decline. Patients were asked consent to use their data for the study. After verbal consent was obtained, written consent was recorded in the patient records, and none declined. When patients dropped out of HaHo, consent was obtained to use data until the moment of dropout. Data were collected from the patient records and anonymised by the principal investigator (PI), using an electronic database, SYMPAL, coding the individual patients' data. The PI was able to link data to individual cases. The methods of consent, data

collection and use of the SYMPAL database for research queries were approved by the local ethics committee of the Utrecht University Medical Centre, the Netherlands (11-113/C).

HaHo

The HaHo service consists of four components. (1) A GP requested home visit from the HNC. The HNC performs a multidimensional assessment; develops a personalised, multidimensional, care plan; and provides specialist support to patients and caregivers. The HNC is available 5 days/week for (un)planned visits. (2) Multidisciplinary consultation, once a fortnight, led by a hospice GP and supported by two HNC. Local GPs, DNs, oncology nurses, a spiritual caregiver and trained volunteers participate in these sessions. To optimise the process, structure and content, HNC and specialist hospice GP provide coaching on the job and training for DNs and GPs in systematic symptom assessment, symptom management and palliative reasoning. The frequency of patient consultation depends on the stability of the patient. To complete HaHo, (3) 24/7 hospice care telephone backup for professionals, patients and caregivers is delivered by the specialist hospice staff. If necessary, patients are guided towards GP out-of-hours services. Furthermore, (4) one healthcare professional, selected by the patient, is responsible for the coordination of care.

To support communication and continuity of care, three documents were developed (A.U., S.T. and E.G.): digital patient record, HaHo database and HaHo agenda. The patient record consists of a multidimensional assessment and a personalised, multidimensional, anticipatory care plan. The HaHo database provides overview of referred

patients including primary diagnosis, patient system stability, end-of-life preferences, patient priorities and the patient preferred care coordinator. The standardised agenda supports the methodological decision-making process during multidisciplinary consultation.

Outcomes and measurements

Expressed end-of-life preferences and the congruence between preferred and actual place of death are the primary outcomes. The expressed end-of-life preference is documented during daily care by DN, GP or HNC, assessed through shared decision-making with the patient and caregivers and documented in categories: home, hospice, hospital, care home, family and friends, or other. Congruence was reached when the location of death equalled the last documented preferred location of death, when the patient was at home. When congruence was not reached, the individual cases were studied qualitatively for reasons of incongruence, for example, reason for admission. Secondary outcomes were symptom burden, (in)stability and early identification. Symptom burden is described through symptom prevalence, clinically relevant symptoms and symptom intensity. To assess symptom burden, the Utrecht Symptom Diary (USD) was used. The USD is a Dutch adapted version of the Edmonton Symptom Assessment Scale, a self-report symptom intensity scale. The USD contains 12 symptoms: pain, sleeping disturbance, dry mouth, dysphagia, anorexia, constipation, nausea, dyspnoea, fatigue, anxiety, and depressed mood and a 1-item wellbeing measure. All symptoms were assessed using a 11-point numerical scale (0=no symptom; 10=worst possible intensity). Symptom prevalence was the proportion of patients scoring a symptom >0 on USD. A cut-off of >3 was used to indicate clinically relevant symptoms.¹⁴ Stability reflected the physical, psychological, social and spiritual status, assessed by the multidisciplinary team, categorised as stable, vulnerable, unstable/critical or in crisis. Early identification was calculated from the period of HaHo enrolment, days from referral to death, the end of the study period or dropout. Baseline characteristics collected at referral were gender, age, primary diagnosis and phase of illness (treatment of illness, symptom management or comfort care).

Data were collected from the HaHo patient record, database, agenda and USD and entered into the SYMPAL database (E.G., A.U.). Data of all patients were imported from the database to an anonymous research file (E.G.).

Statistical analysis

Data were analysed using descriptive statistics. Data triangulation was performed using the HaHo patients records, database and agenda. All data were checked on congruence

Table 1. Patient characteristics, stability and early referral.

Characteristics	N (%)	Mean (SD)
Gender		
Male	62 (48)	
Age (years)		72 (12.1)
Age categories (years)		
<65	33 (26)	
65–74	36 (28)	
75–84	41 (32)	
≥85	19 (15)	
Primary diagnosis		
Cancer	116 (89)	
Renal failure	1 (1)	
Lung failure COPD	4 (3)	
ALS	2 (2)	
Heart failure	1 (1)	
Dementia	1 (1)	
Other	3 (2)	
Missing	2 (2)	
Phase of palliation ^a		
Treatment of illness	20 (15)	
Symptom management	93 (72)	
Comfort care	17 (13)	
Stability ^b		
Stable	18 (14)	
Vulnerable	59 (45)	
Instable	39 (30)	
In crisis	11 (8)	

SD: standard deviation; COPD: chronic obstructive pulmonary disease; ALS: amyotrophic lateral sclerosis; HaHo: hospice assist at home.

^aThe phase of palliation is identified by the aim of care and treatment within palliative care.

^bMultidimensional assessment of the patients stability according the HaHo caregivers, discussed during the multidisciplinary consultation.

between data sources. Incongruence was discussed with the coordinating healthcare professional, to enhance the quality of data (E.G., G.U.). Data analysis was performed using IBM SPSS statistics (E.G., S.T.).

Results

In total, 130 patients (62 (48%) men, aged 72 (37–96, standard deviation (SD): 12.1) years) were enrolled (Table 1). During HaHo enrolment, 92 (71%) patients were visited by the HNC at home, 25 (19%) patients were visited by HNC as well as discussed during multidisciplinary consultation. A total of 28 (22%) patients were discussed in one or more multidisciplinary meetings. Five patients (4%) dropped out of HaHo due to switch to curative intent ($N=2$), stable disease ($N=2$) and psychological distress with regard to confronting illness ($N=1$).

Cancer was the primary diagnosis (89%). On referral, the aim of treatment and care was mainly symptom

Table 2. Congruence between preferred and actual place of death.

Preferred place of death	Actual place of death			
	Home, N (%)	Hospice, N (%)	Hospital, N (%)	Total, N (%)
Home	70 (91)	4 (5)	3 (4)	77 (72)
Hospice	2 (9)	21 (91)	0	23 (21)
Home or hospice	0	1 (100)	0	1 (1)
Unknown	3 (50)	0	3 (50)	6 (6)
Total	75 (70)	26 (24)	6 (6)	107

Table 3. Symptom burden on referral.

	Prevalence, N (%) ^a	Clinical relevance, N (%) ^b	Intensity, mean (SD)
Pain	49 (70)	25 (36)	2.72 (2.497)
Sleeping problems	40 (57)	24 (34)	2.61 (2.882)
Dry mouth	42 (60)	29 (41)	3.03 (3.018)
Dysphagia	16 (23)	6 (9)	0.83 (1.819)
Anorexia	52 (74)	42 (60)	4.48 (3.016)
Constipation	38 (54)	22 (31)	2.42 (2.714)
Nausea	30 (43)	13 (19)	1.60 (2.425)
Dyspnoea	24 (34)	17 (24)	1.97 (3.187)
Fatigue	66 (94)	58 (83)	6.31 (2.394)
Anxiety	21 (30)	10 (14)	1.29 (2.339)
Depressed mood	42 (60)	24 (34)	2.64 (2.684)

SD: standard deviation; USD: Utrecht Symptom Diary.

^aPatients scoring over 0 on USD at referral.

^bPatients scoring >3 on USD at referral.

management (72%): less frequently treatment of illness (15%) and for 17 (13%) patients comfort care, of whom 2 patients died on the day of referral.

Place of death

Patients enrolled in HaHo preferred to die at home (68%) or in hospice (22%). For 12 (9%) patients the preferred place of death was not known. During the study, 107 out of 130 patients died, their end-of-life preferences were home (77%), hospice (23%), hospice or home (1%) or unknown (6%). Data on their actual place of death showed that 75 (70%) patients died at home, 26 (24%) patients died in a hospice and 6 (6%) patients died in a hospital. Congruence between preferred and actual place of death was reached in 92 (86%) patients. If the preferred place of death was known, 92/101(91%) patients died in their preferred place of death. Table 2 shows an overview of preferred versus actual place of death.

Differences between actual and preferred place of death was found in 15 (14%) patients. The main reason was an unknown preferred place of death. Patients were unable to discuss death and dying ($N=6$), of whom three patients died in a hospital and three died at home. Four patients preferred to die at home, but died in a hospice after a planned admission for respite care ($N=3$) or last resort,

because patient and family carers were in crisis and unable to stay at home ($N=1$). Three patients, who preferred to die at home, died in a hospital due to a medical emergency not related to their primary illness ($N=2$) and a multidimensional crisis ($N=1$). Finally, two patients wanted to die in a hospice but died at home, as their deaths came calm and there was no urge to transfer.

Symptom burden

During HaHo, 298 USD were filled out by 70 unique patients. On referral, patients suffered from six symptoms concurrently, of which four symptoms were clinically relevant. Fatigue was most prevalent in 94% of patients. Other highly prevalent symptoms were anorexia 74% and pain 70%. Most intense symptoms were fatigue 6.31(SD: 2.394), anorexia 4.48 (SD: 3.016) and dry mouth 3.03 (SD: 3.018). Wellbeing was low, scoring 4.97 (SD: 2.429) on average. Symptom burden at referral is shown in Table 3.

Stability

When referred to HaHo only 18 (14%) patients were identified as 'stable'. Most patients were either vulnerable (45%) or unstable (30%). Eleven (8%) patients were in crises at referral.

Early identification

The median length of referral was 61.5 days (mean: 119.8; range: 0–911; SD: 163.5). Median survival was 59.5 days (mean: 102.7; range: 0–671; SD: 132.7) from enrolment to death of 107 patients who died.

Discussion

HaHo integrates general palliative care and specialist palliative care in primary care by interdisciplinary collaboration, consultation and 24/7 telephone support from specialist hospice staff. During the first 2 years, 130 patients were referred to the service. The preferred place of death was known for 94% patients, of whom 91% died in their preferred location. This study shows that an integration of general and specialist palliative care services in the community can support patients to express their end-of-life preferences and die in their preferred location.

Strengths and weaknesses

We have to make several considerations on strengths and weaknesses. A strength is that it reflects the real life care environment experienced by patients and their families, since HaHo was initiated and developed by professionals working in daily practice. The HaHo service continued to develop during the 2 years of the study as needed to adapt to the local primary care. Due to this changing, dynamic process, a retrospective descriptive design was the most suitable strategy for this study. While we aimed to develop structured documents to support methods and content of HaHo, these documents were developed in close collaboration between the professionals and researchers.

Using an observational design, we were not able to draw solid conclusions, because this design is not suited to detect causality. Nevertheless, we were able to compare our outcomes with previous studies in similar study population.

The period of enrolment is characterised by a broad range, and the primary diagnosis was cancer. Comparing patient characteristics to the Dutch patients who died, the very old and chronically ill were under-represented in our study population.¹⁵ These results might indicate that early identification of patients at home was sub-optimal and more patients in the community could benefit from HaHo. Although the ‘surprise question’ was used to identify all patients with a life expectancy of less than 1 year, we cautiously conclude that we have not identified all patients within the target population. An improvement to HaHo would be to systematically assess all patients within the general practice with palliative care needs. As per lessons learned from the Gold Standard Framework, levels of adoption will continue to differ between GPs.¹⁶ Specialist practice nurses working in the GP practice could be the key to overcome these barriers, leading to early identification of the frail elderly and patients suffering from chronic illness.

Finally, like all studies, the generalisation of our results has to be considered with caution, due to the specific characteristics of the Dutch healthcare system.

Congruence between actual and preferred place of death

In congruence with international studies, our study shows that most patients prefer to die at home,^{17,18} and the congruence between the preferred and actual location is high when a preferred location is known.^{15,18} In addition to previous studies, 94% of the patients had explicit preferences for place of death towards the end-of-life, which contributed to dying on their preferred place of death.¹⁵

Anticipatory care, including communication about end-of-life care preferences, is recognised to be important in primary care. However, GPs state it is difficult to find the right timing to initiate a conversation.¹⁹ In our study, the only barriers to proactive communication were patient-related factors: not able (too ill) or not willing to communicate (too confronting, denial). These differences can be explained by the multidisciplinary collaboration of the service; anticipatory care was not only performed by the GP, but it was a shared responsibility within the team. This continuous attention to patient’s preferences led up to 94% of patients expressing their preferred place of death, which is high when compared to previous studies. Studies of representative Dutch patients who died from 2009 to 2011 found known preferences for 54%–72% patients.^{5,18,20} Internationally, Bell et al.²¹ found only three studies where all patients expressed their preferences, and 13 studies 35%–82% of patients expressed their preferences. Therefore, HaHo seems to empower patients and caregivers to express their preferences during the active supported palliative care trajectory.

Early identification

HaHo patients suffered from over six symptoms concurrently, of which over four were clinically relevant. The symptom burden of HaHo patients is comparable to the symptom burden of Dutch hospice inpatients on referral.²² The multidimensional stability of patients was vulnerable or unstable, and 8% of patients were in crisis. Both indicate that patients referred to HaHo had specific and complex palliative care needs and could benefit from combined general and specialist palliative care.

HaHo integrates general and specialist palliative care to overcome challenges within a local healthcare system. As a result, we enabled patients to express and die at their preferred place of death. Gardiner et al.²³ identified communication, shared learning, coordination, definition of roles and responsibilities and timely access to specialist palliative care services, as success factors for collaboration. Although HaHo entails a framework, requiring these

factors, the working mechanism of the components was not studied.

To conclude, this study suggests that HaHo enabled patients to express their preferred place of death and to die at their preferred place of death. Areas for future study include (1) the analysis of the successful and unsuccessful components of the HaHo service in order to develop the model of integrative general and specialist palliative care more elaborately and (2) further study of the patterns and course of symptoms in order to better understand the interventions required from the multidisciplinary team in order to optimise the patients' quality of life.

This study emphasises the need for a conscientious role for specialist hospice services to support high-quality palliative care within the local primary care system. Using an integrative approach which does not take over responsibilities, but confirms established relationships with GP, DNs and volunteers, realises interdisciplinary collaboration in generalist and specialist palliative care.

Acknowledgements

The authors would like to express our thanks to the patients who took part in this study and the dedicated HaHo formal and informal caregivers who made it possible.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

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