Who are hospice patients and which care is provided?

A pilot study

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Abstract

Background: Hospices in the Netherlands provide multidimensional care. Patients with <3 months estimated life expectancy have access to hospice care. Insight into the patients admitted to hospices and the care provided is lacking. In preparation of a large multicentre study, a pilot study was performed.

Objective: Primary objective of this study was to test the appropriateness of the 1) study procedures, 2) the outcomes patient and care characteristics.

Method: A cross-sectional pilot study was performed, using a descriptive explorative design. Fifteen hospices were invited to participate, the hospice patient records (HPR) from 8 patients per hospice were selected. Data was collected using self-developed (electronic-)case report form's.

Outcomes:

1) Appropriateness of procedures: availability of HPR, identified barriers and strategies used to obtain the HPR.

2) Appropriateness of patient and care characteristics: the availability of the characteristics in HPR. Per item the availability was assessed as being directly available, contextual extraction was possible, or not available at all.

Results: In total 104 patients from thirteen hospices were enrolled. The nurses' records were most available (98%), in contrast to records of volunteers (62%). Barriers in data were: a lack of knowledge on research, no access to records, ICT- and communication problems. Deployed actions were conversations with legal employees or approaching hospices from a higher level of influence. Information of the illness was most available (97%) in HPR. Experienced symptoms were the least available (10%).

Conclusion: Although hospices are willing to participate, collecting HPR specifically from homecare organisations and GP was difficult and took time. Patient and care characteristics were diversified available. Final conclusion is that piloting was an important step to inform and adjust study procedures and outcomes to ensure study success of the large multicentre study.

Key Words: Palliative care, hospice care, pilot, medical records, data collection.

Samenvatting

Achtergrond: Hospices in Nederland leveren multidimensionale zorg. Patiënten met een levensverwachting van < 3 maanden hebben toegang tot hospice zorg. Inzicht in patiënt- en zorg karakteristieken ontbreekt. In voorbereiding op een groot multicenter studie, is een pilotstudie uitgevoerd.

Doelstelling: Primaire doel van deze studie was om te testen of 1) studie procedures, 2) de uitkomsten patiënt en zorg karakteristieken, geschikt zijn binnen een groot retrospectief dossieronderzoek.

Methode: Een cross-sectionele pilot is uitgevoerd, gebruikmakend van een beschrijvend en exploratief design. Vijftien hospices zijn uitgenodigd om te participeren, waarvan 8 patiëntendossiers per hospice werden geselecteerd. Data is verzameld door middel van zelf-ontwikkelde data extractie formulieren.

Uitkomstmaten:

1) Geschiktheid van procedures: beschikbaarheid van patiëntendossiers, geïdentificeerde barrières en strategieën om patiëntendossiers te verzamelen.
2) Geschiktheid van patiënt- en zorgkarakteristieken: Beschikbaarheid van deze karakteristieken in patiëntendossiers. Per item werd beoordeeld als: direct beschikbaar, extractie uit context is haalbaar of niet beschikbaar.

Resultaten: In totaal zijn dossiers van 104 patiënten uit verschillende 13 hospices verzameld. Dossiers van verpleegkundigen waren het meest beschikbaar (98%), in tegenstelling tot dossiers van vrijwilligers (62%). Barrières tijdens dataverzameling waren: gebrek aan kennis over onderzoek, geen toegang tot dossiers, ICT- en communicatieproblemen. Ingezette acties waren gesprek met juridische medewerkers of hospices benaderen vanaf een hoger niveau van invloed. Informatie over de ziekte was het meest beschikbaar (97%) in patiëntendossiers. Ervaren symptomen het minst beschikbaar (10%).

Conclusie: Hoewel hospices bereid waren om te participeren, was het verzamelen van patiëntendossiers van thuiszorgorganisaties en huisartsen moeilijk en kostte tijd. Patiënt- en zorgkarakteristieken waren afwisselend beschikbaar. Uiteindelijke conclusie is dat deze pilotstudie een belangrijke stap was om te informeren over studieprocedures en uitkomsten, ze aan te passen, zodat het succes van de grote multicenter studie wordt verzekerd.

Trefwoorden: Palliatieve zorg, hospice zorg, pilotstudie, patiëntendossiers, data verzameling.

Introduction

In 2017, approximately 149.400 people died in the Netherlands and numbers will increase to over 200.000 people in 2050[1]. Estimating that more people will die a non-sudden death, the need of palliative care will become more important[2,3]. Palliative care is defined as: *'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual[4]'.*

Worldwide, two levels of palliative care exist[2], namely: 1) generalist palliative care – is offered by caregivers as part of their daily practice, which received, often minimal, basic palliative care training in their initial education, and 2) specialist palliative care – an advanced palliative care level, provided by caregivers who predominantly provide palliative care[2]. Hospice care (HC) is specialised palliative care. In the Netherlands there are approximately 300 hospices[5], which is provided by both volunteer-driven hospices (VDH) as well as professional-driven hospices (PDH). In VDH, daily care is provided by trained volunteers and family members. If necessary, medical care is provided by the patient's own general practitioner (GP) and district nurses[6]. PDH are divided in palliative care units (PU) and High-Care-Hospices (HCH). PU are specialised wards in nursing homes and HCH are small scale, stand-alone, care-organisations. Daily care is provided by a multidisciplinary team, consisting of a nursing staff, specialised palliative care nurses, physicians specialised in palliative care (of geriatric medicine) and supplemented with care of (trained) volunteers. An overview of palliative- and HC in the Netherlands is described in Figure 1.

(Figure 1).

HC is multidimensional care and the organisation of care differs largely between VDH, PU and HCH, insight into patient and care characteristics is needed[7]. Although no differences are found in age, gender and main diagnoses between the types of hospices[8], still a complete image of which patients are admitted and which care is provided, is missing. To examine similarities and differences between the types of hospices, a large retrospective multicentre study will be performed, examining hospice patient records (HPR) of HC inpatients. This study is part of the HOPEVOL study (phase II), which consists of five phases (as shown in figure 2), and will examine patient and care characteristics under 500 HPR per type of hospice[7].

HC can be considered a complex intervention entailing multiple components, multiple disciplines and a heterogeneous patient population[9]. The Medical Research Council (MRC) developed a framework to support the development of complex innovations[10]. Although piloting in the MRC framework is mostly related to the performance of an effect study, the performance of a pilot study in preparation of a large retrospective multicentre study in a complex field which has rarely been studied, could contribute to a successful study[10]. Besides, it is likely that there is a wide range of how HPR are operationalised, due to different disciplines, who keep their own HPR, available on their own workplace. For example, district nurses have different HPR then GP's. It is possible that multiple records exist on different locations, for one HPR. Therefore, the availability for HPR, possible barriers, and necessary actions to obtain these records are crucial to collect. The aim of this pilot study was to inform and adapt the study procedures and outcomes to fit the variance in current hospice practices and to ensure study success for the large multicentre study performed afterwards[11].

Objectives

Primary objective

Primary objective of this study was to test whether the study procedures and the outcomes patient characteristics (demographics, illness characteristics, experienced symptoms) and care characteristics (indications for deployment of (non-)pharmacological interventions and used assessment tools) are appropriate to be used in a large multicentre study on HC and hospice patients in the Netherlands.

Therefore, the sub-objectives were:

- Gain insight into the availability of HPR;
- Gain insight into the availability of information regarding patient characteristics and care characteristics in HPR;
- Describe barriers and necessary actions during data collection of HPR and patient data from hospices.

Secondary objectives

Secondary objectives were to describe patient characteristics (demographics, illness characteristics, experienced symptoms) and care characteristics (indications for deployment of (non-)pharmacological interventions and used assessment tools).

Methods

An explorative, descriptive pilot study has been performed from December 2017 to June 2018 using a cross-sectional design. This study had a quantitative approach, due to describe the administrative information in data collection[11]. For primary objectives a cross-sectional design was chosen, to capture data at a single time point, so it provides insight into current documentation from doctors, nurses and volunteers[11,12]. Using records of patients who already received care in hospices, it was possible to gain insight into the availability of records and characteristics in the documentation. Since no previous research has been done, a descriptive explorative design was most fitting[11,13]. Besides the quantitative items, several qualitative items were collected, where information on possible classifications was lacking. For secondary objectives a retrospective design was used, using the same methods as the final study performed in HOPEVOL phase II. So, study procedures and outcomes were tested for the final study. To ensure the completeness of this report, the guidelines outlined in the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) were used[14].

Population and domain

This study was conducted among three types of Dutch hospices, namely VDH, PU and HCH, using convenience sampling to select hospices. The population of this study consisted of patients who received palliative care in hospices. HPR were included when patients 1) received care in one of the three types of hospices and 2) were admitted and died in a hospice in 2017. Records from all involved disciplines were examined[7]. Patients who received outpatient palliative care were excluded from the study. To gain in-depth information, hospices selected four HPR that they felt were a typical reflection of patients admitted and care provided in their hospice. In addition, four HPR were selected at random[7]. This study intended to include fifteen hospices, to collect 120 HPR in total. For this pilot study patient and care characteristics within the three types of hospices were not compared.

Data collection

Primary outcomes were defined as: 1) availability of HPR, 2) availability of patient- and care characteristics. A description of patient and care characteristics were secondary outcomes.

Availability of HPR

Firstly, availability of HPR was determined (dichotomous). Secondly, if HPR were not available, barriers and necessary actions were collected. Finally, if HPR were available after actions were deployed, availability of HPR was measured again.

Availability of patient characteristics and care characteristics

The availability of patient characteristics was defined as the description of specific items in HPR. Availability was categorised per item as described in Box 1. Patient characteristics were operationalised in demographics, illness characteristics and experienced symptoms. Care characteristics were defined as the indications for deployment of (non-)pharmacological interventions and used assessment tools. Patient and care characteristics were in concordance with the study proposal of the multicentre study.

(Box 1).

Description of patient and care characteristics

Patient characteristics were defined as demographics, illness characteristics and experienced symptoms (physical, psychological, social and spiritual). Experienced symptoms were assessed using the four-dimensional Utrecht Symptom Diary (USD4D)[15]. The USD4D entails eleven symptoms, a one-item well-being measure, complemented with five social and spiritual items on an eleven point numerical scale.

Symptoms were defined prevalent when scored one or higher and clinically relevant when scored three or higher on USD4D. Care characteristics were collected, looking at indications for deployment of (non-)pharmacological interventions and used assessment tools. Care characteristics were collected from the first 72 hours after admission.

Measurements

Data extraction forms were specifically designed for this study. Availability of HPR were measured using a case report form (CRF). Availability of characteristics and secondary outcomes were measured using an electronic case report form (eCRF). All variables are described in Appendix 1. Before data collection, (e-)CRF's were tested and adjusted. The first five cases were discussed within the research team to reach consensus on the assessment and notation of the items. Thereafter, agreed rules of notation were described in a codebook and study procedures.

Procedures

Information letters were sent through the umbrella organisations to invite hospices to participate in the study. In addition, hospices were invited by network coordinators palliative care through personal contact. If hospices were willing to participate, researchers sent additional information. After hospices agreed to participate, personal contact was made by the researchers, to make an appointment for data collection. All patients who met the

inclusion criteria were assigned a number. Patients selected by the hospice were excluded for randomisation. Randomisation took place on the day of data collection, using Research Randomizer (Version 4.0)[16], which corresponded with the overview of patients admitted and died in 2017. In some cases, randomisation was performed before the day of data collection, so non-available HPR could be gained access to. An anonymised overview of patients was sent through a secured file by mail. After randomisation, researchers contacted the concerning GP and hospices contacted the homecare organisation(s) for participation of the specific patient. If participation was agreed, appointments were made about how HPR were conveyed to the hospice in dispute or alternatives to obtain these records. Data collection was performed at the hospice site and collected by two researchers at the time. A confidentiality statement was signed by the researchers per hospice.

Data analysis

For primary outcomes, availability of HPR and characteristics were analysed using descriptive statistics. Barriers and necessary actions were analysed qualitatively and categorised afterwards. Continuous data, if normally distributed, are presented with means and standard deviations. If not normally distributed, data are presented by medians and interquartile ranges. Categorical data are presented with absolute frequencies and percentages. All data were checked on normality, using histogram plots. Missing items were not imputed since missing data were a part of the primary outcome of this study.

For secondary outcomes, quantitative items were analysed using descriptive statistics. Qualitative items were categorised, quantified and analysed with descriptive statistics. An example of categorisation is given in Box 2. Data were analysed using IBM SPSS Statistics version 24,0 (Armork, New York, USA).

(Box 2).

Ethical issues

This study was conducted according to the principles of the Declaration of Helsinki (64th version, October 2013)[17], the Medical Research Involving Human Subjects Act (WMO)[18] and the agreement on medical treatment act (WGBO)[19]. The research protocol (reference-number WAG/mb/18/004837) was assessed as not WMO-obligatory by the Medical Research Ethics Committee in Utrecht. File research applies to the legislation of the WGBO[19]. Therefore, no informed consent had to be obtained, due to collecting HPR of diseased patients (Dutch civil code, Book 7, Title 7, Department 5, Article 458)[20]. Local consent was obtained from hospices. To pursue scientific integrity the study was conducted

according to the principles of Good Clinical Practice (GCP)[21]. Full anonymisation was not possible, due to re-accessing records in the final study[7]. Therefore, key data were stored on a separate server, specifically for private study data, according to data management regulations of the Julius Center Utrecht. Data of eCRF's were gathered on an enclosed server, using an online data-management system. This system has been closed after the study and data is stored, on a server of the Julius Center for the coming fifteen years.

Results

Thirteen hospices participated in the study, consisting of five HCH, six PU and two VDH. Three VDH wanted to participate in the study, but homecare organisations or GP's refused for participation. Median admissions in 2017 was 75 (IQR: 27,8) patients per hospice. Hospices had an average capacity of 8 beds (SD: 2,5). Of these hospices twelve (92%) used a digital HPR system. In total 104 HPR were obtained, whereof 60/104 patients were female. Patient's mean age was 73 (SD: 15,4) and were admitted with a median of 20 days (IQR: 47,5). Other baseline characteristics are presented in Table 1.

(Table 1)

Availability of HPR

From the participating hospices 99/104 of records from doctors, 102/104 of records from nurses and 64/104 of records from volunteers were available for data collection. It took 21,7 days (SD: 14,9) on average to obtain HPR. Generally, it took longer to obtain HPR in VDH ($\tilde{x}$ = 34) than in PU ($\tilde{x}$ = 26) and HCH ($\tilde{x}$ =12).

The four main categories of barriers were: 1) a lack of knowledge on research, 2) ICT problems, 3) communication problems and 4) no access to HPR. An overview of main categories and specific barriers are described in Box 3.

(Box 3)

Necessary actions to gain access to HPR were 1) conversations with legal employees, 2) contact with the ICT department for credentials, 3) contact with the medical secretary department, 4) telephone contact to provide more information about the study and 5) signing a hospitality statement. If an action was needed, it was executed by the researchers, the specialist elderly care or by the contact of the hospice in dispute.

Availability of patient characteristics

Demographics

Age and gender were always described in the HPR. Consecutively, marital status was described in 98 (94%) HPR. Length of hospice stay was described in 100 (96%) HPR, extracted from context in three HPR and not available for one patient, due to missing the date of dismission. Other variables were mostly described in HPR or could be extracted from context. An overview of the available demographics is provided in Table 2.

(Table 2)

Illness characteristics

In total, 14 of 24 variables of illness characteristics were available over 50% in HPR. All variables are displayed in Table 3. Illness characteristics were most available (97%) in HPR, with 100% availability of main diagnoses. While information on multidimensionality was available in 47% of HPR. Patient worries were mostly not available (81/104) in HPR. Information about dying was 68% available in HPR, of which individual variables were high in availability, except for preferred location of dying and changed preferred location, resp. 53% and 13%. The stage of the illness was mostly extracted from the context (50/104). The availability of information describing problems during admission was high (88/104 HPR).

(Table 3)

Experienced symptoms

Information describing experienced symptoms was available in ten HPR.

Availability of care characteristics

Indications for deployment of (non-)pharmacological interventions

In 100/104 HPR indications for deployment of (non-)pharmacological interventions were described. In three HPR interventions could be extracted from the context and interventions from one HPR are not available.

Used assessment tools

In 46/104 HPR used assessment tools were available in HPR and in 55/104 HPR they were not available. Researchers did not fill in the used assessment tools for three HPR, therefore labelled as missing.

Description of patient characteristics

Patients were predominantly married/registered partnership (43/104) or widowed (21/104). Before admission most patients lived alone (n=47, 45%). Most patients stayed at the hospital before admission (n=53, 51%) or were admitted from home (n=38, 37%). Description of demographics is summarized in Table 4.

(Table 4)

Initiative for hospice admission was mostly taken by patients themselves and/or by their family (n=53, 51%). The aim was predominantly last resort (n=100, 96%). Mostly, patients suffered from cancer (n=82, 80%), specifically digestive system (n=25, 24%) or lungs (n=24, 23%). Mainly, patients received symptom targeted palliation (n=89, 86%). The median period between marking the palliative phase and hospice admission was 27 days (IQR: 157). The most frequently experienced problems during admission were: delirium (n=30), pressure ulcers (n=24) and oedema (n=19). During admission, patients felt supported by their closest ones (35/104) and/or by their religion (23/104). End-of-life decisions performed were palliative sedation (52/104) and euthanasia (5/104). An overview describing all illness characteristics is provided in Table 5.

(Table 5)

Experienced symptoms

All available USD4D's were completed by care providers, not by patient's themselves or their family members. Most prevalent symptoms were anorexia (n=10), dry mouth (n=9) and constipation (n=7).

Description of care characteristics

A total of 630 deployed interventions were described in HPR (297 pharmacological, 333 non-pharmacological), during the first 72 hours after admission. Per patient, on average, six interventions were deployed. Interventions were mostly deployed in the physical dimension (n=408, 65%), and least in the spiritual dimension (n=8). Most deployed interventions were focused on pain (n=91), (prevention of) pressure ulcers (n=59) and dyspnoea (n=29). A total of eleven different assessment tools were described of which the Karnofsky-score, USD4D and OMAHA screening were mostly used, resp. n=20, n=10 and n=9. A top-ten of indications for (non-)pharmacological interventions and a top-five of used assessment tools are described in Box 4.

(Box 4)

Discussion

The aim of this study was to pilot test whether the study procedures and the outcomes of patient and care characteristics are appropriate to be used in a large multicentre study on HC and hospice patients. Therefore, insight into the availability of HPR was examined. HPR of nurses were most available (102/104), and the least of volunteers (64/104). Four main categories of barriers were identified: a lack of knowledge on research, no access to records, ICT- and communication problems. Demographics were mostly available in HPR or could be extracted from the context. In total, 14 of 24 variables of illness characteristics were available over 50%. Availability of experienced symptoms was described in ten HPR. Deployment of (non-)pharmacological interventions was described in 96/104 HPR. Used assessment tools were available in 46/104 HPR.

Strength and limitations

The strength of the present study is performed in a realistic setting, which gives a glimpse of the current practice in hospices. Besides, during data collection, multiple cases were discussed within the research group, consensus was reached and rules of notation were described in a codebook. Furthermore, a full scope of all possible classifications is obtained, due to open variables, which were categorised and quantified.

However, some considerations have to be made. First, items were selected through previous research and based on a specific electronic patient system. Some specific items were not available in other kinds of electronic patient systems if extraction from context was not possible. Second, only data from the first 72 hours after admission were collected, due to feasibility of the study. Therefore, information about specific characteristics could be missed. Third, using the USD4D as a measurement instrument for experienced symptoms, resulted in a low availability. At last, generalizability is limited, due to the lack of VDH in the sample.

Piloting

To the best of our knowledge no previous research has been done on the availability of HPR and patient/care characteristics in HC. This pilot has a crucial function on informing the multicentre study in the HOPEVOL project, to test the feasibility of methods, procedures and protocols and outcomes[22]. Even though piloting is not common for this kind of research, this pilot created insight into the availability of 1) HPR 2) patient and care characteristics and 3) barriers that were present during data collection. Based on this knowledge and if planning, procedures and outcomes are adjusted, the success rate of the final study will increase[11,22].

Hospice patient records

In total, 104 HPR (from 13 hospices) instead of the planned 120 HPR were collected. HPR made by volunteers were least available, due to multiple possible explanations. First 1) volunteers do not write reports, 2) reports were annulled or 3) reports were given to family after death of the patient. Furthermore, questions and concerns about the ethical delayed the performance of this study. A potential factor could be the effect from the new law of general data protection regulation[23]. Although hospices were willing to participate in the study, some homecare organisations and GP's were holding back or refused participation. This resulted in a tension between researchers and hospices, which led to a loss of control on communication for researchers. Sometimes, approaching hospices from a higher level of influence was needed, e.g. by network coordinators or high placed members of the umbrella organizations.

Despite that 92% of the hospices work with an electronic HPR system, most hospices work with multiple systems for documentation by physicians and nurses. Thereby, in VDH per patient, documentation was obtained from multiple places. Records from GP's had to be obtained at the general practice or were sent to the hospice. The same applies for records from homecare organisations. To conclude, no HPR is the same.

Patient characteristics

For clinical practice, it is striking that hospices strive for multidimensional care, whereas availability of multidimensional characteristics was minimal. This is in line with an earlier study about multidimensional care in HPR[24]. The psychological, social and existential dimensions, other than the physical dimension, were under-documented. Specific variables on this topic were low in availability. A possible reason might be that nurses only describe these items when problems on this matter occur. Secondly, discussion of the palliative marking was little available (47%), possibly because this takes place before hospice admission. At last, availability on experienced symptoms was low, due operationalisation with the USD4D. Possible reasons are that the USD4D is not a standard of care in all hospices and that not all USD4D were available within the first 72 hours after admission.

Care characteristics

Interventions were mostly deployed on the physical dimension and the least in the spiritual dimension. This corresponds to previous research that physicians are trained to address physical problems primarily[24]. Besides that, other interventions were not documented because nurses interpreted these interventions as usual care[24].

In less than half the assessment tools were available in HPR. Previous research showed that 10/12 professional-driven hospices used assessment tools[24]. Although this study examined within the three types of hospices, there is still an under-representation of volunteer-driven hospices and further research is needed.

Recommendations

In the final study it is recommended to pay extra attention to communication with hospices and providing extra information on concerns on ethical issues and justification of choices made. Furthermore, calling hospices a day before data collection could ensure that everything is arranged properly and to prevent new barriers. Third, based on the period between first contact to VDH and obtaining records of GP's and district nurses are more difficult and takes longer to be available for data collection. Therefore, researchers should consider that the timing between first contact and data collection of VDH is longer than the other types of hospices and should be adjusted in the planning for the final study. Finally, qualitative sampling could enrich the data, e.g. using observations, shadowing or focus-groups.

Conclusion

To conclude, hospices are willing to participate in the study. However, GP's and homecare organisations were sometimes holding back or refused participation. Therefore, it takes much effort to enrol hospices in a study to obtain HPR. Procedures of this study are operable for the final study, but data collection takes an effort in time, communication and flexibility. Presented barriers during this study were a lack of knowledge on research, no access to records, ICT- and communication problems. Patient and care characteristics were diversified available. Final conclusion is that piloting was an important step to inform and adjust study procedures and outcomes to ensure study success of the large multicentre study.

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Tables and Figures

Organisational Structure	Volunteer-driven hospice	Professional-driven hospice	
		Stand-alone	Hospice-unit nursing home
Association	Volunteers Palliative Terminal Care	Dutch Association of Hospice Care	Actiz
Access	Patients with an estimated life expectancy <3 months		
Staff	Trained volunteers 24/7 and Patients' general practitioner District nurses	Specialized nurses 24/7 Physicians (GP, medical specialist, elderly care specialist), chaplain, paramedical and supportive specialists Supported by trained volunteers	

Figure 1: Palliative- and hospice care in the Dutch healthcare system, De Graaf et al. 2016[24].

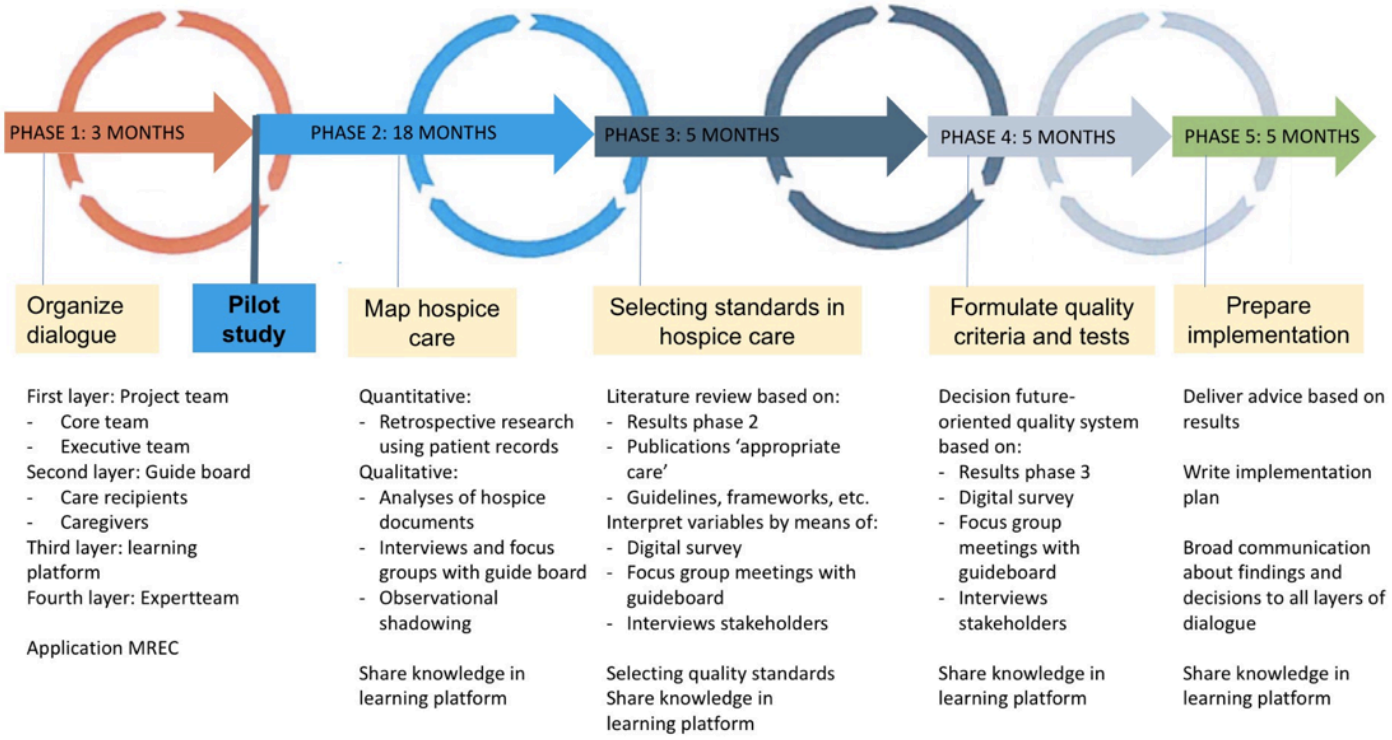

Figure 2: Phases of the project HOPEVOL.

Box 1: Operationalisation of availability of patient data per item.

Code:	***Operationalisation:***
Available	Described in hospice patient record (HPR)
Context	Not present in HPR, but extraction from context was possible.
Not available	Not present in HPR, nor extraction from context was possible
Not applicable	Specific item is not applicable for the patient
Missing	Missing value by researchers

Box 2: Examples of analysing qualitative times into categories.

Collected qualitatively:	***Category:***
Lives together with partner *Lives with spouse* *Home with friend*	Living together
Lives alone *Lives alone with help from community care*	Single

Table 1: Demographic data of hospices.

Variables:	***n(%)***	***Mean (SD)***
Type of Hospice		
- *HCH*	5 (39%)	
- *PU*	6 (46%)	
- *VDH*	2 (15%)	
Number of admissions in 2017		75 (27,8)*
Number of beds		8 (2,5)
Numbers of years after opening		13 (6,6)
Team formation		
- *Number of doctors*		2 (1,6)
- *Number of nurses*		14 (8,4)
- *Number of volunteers*		78 (60,0)*

* Median (Interquartile range), due to not normal distribution

Box 3: Presented barriers during data collection.

Main categories:	**Barriers:**
Lack of knowledge on research	Primarily not willing to participate based on ethical issues; No overview available of patients who were admitted and passed in 2017; Cancelling of participation in study.
ICT problems	No credentials to PC and/or specific electronic hospice patient record (HPR) system; Not enough credentials to PC and/or specific electronic HPR system.
Communication problems	Not directly in contact with right person; First appointment for data collection was cancelled, due to communication failure of the hospice; Appointment was forgotten by GP; Unclear if patient's own GP or GP from hospice was head practitioner.
No access to records	Volunteers do not report in HPR; Annulation of records made by volunteers; Wrong HPR; Name of GP is only available in records from district nurses; Person responsible for research is not available for 2 weeks.

Table 2: Availability of patient characteristics.

	Degree of availability			
Variables of patient characteristics (n, %)	**Available**	**Context**	**Not available**	**Missing**
Gender	104 (100%)			
Age	104 (100%)			
Marital status	98 (94%)	5 (5%)	1 (1%)	
Living situation before admission	86 (83%)	17 (16%)		1 (1%)
Residence before admission	96 (92%)	6 (6%)	2 (2%)	
Length of hospice stay	100 (96%)	3 (3%)	1 (1%)	

Percentages are rounded and therefore may not add up to 100.

Table 3: Availability of illness characteristics.

	Degree of availability (n, %)				
Information about:	**Available**	**Context**	**Not available**	**Not applicable**	**Missing**
Admission ($\tilde{x}$=50%*)					
Initiating person	45 (43)	29 (28)	30 (29)		
Initiating professional	26 (25)	8 (8)	15 (14)	55 (53)	
Goal of admission	58 (56)	43 (41)	3 (3)		
Reasons for admission	80 (77)	20 (19)	3 (3)		1 (1)
Dying ($\tilde{x}$=68%*)					
Reasons dismission	99 (95)	4 (4)			1 (1)
Use of end-of-life-care	87 (84)	8 (8)	4 (4)		5 (5)
Passed during admission	98 (94)	6 (6)			
Preferred location of dying	55 (53)	16 (15)	33 (32)		
Changed preferred location of dying	13 (13)	9 (9)	79 (76)		3 (3)
The illness ($\tilde{x}$=97%*)					
Main diagnoses	104 (100)				
Actual co-morbidity's	97 (93)	1 (1)	6 (6)		
Multidimensionality ($\tilde{x}$=47%*)					
Orientation	61 (59)	22 (21)	21 (20)		
Memory problems	44 (42)	25 (24)	35 (34)		
Memory problems specification	44 (42)	7 (6)	20 (19)		33 (32)
Patient worries	16 (15)	7 (7)	81 (78)		
Support from closest ones	28 (27)	21 (20)	55 (53)		
Support religion	76 (73)	1 (1)	27 (26)		
Support religion specification	74 (71)	1 (1)	25 (24)		4 (4)
Palliative marking ($\tilde{x}$=62%*)					
Date marking palliative phase	86 (83)	5 (4)	12 (12)		1 (1)
Discussed with patient	49 (47)	18 (17)	37 (36)		
Life expectancy	79 (76)	3 (3)	22 (21)		
Stage of the illness	50 (48)	50 (48)	4 (4)		
Disease target therapy	59 (57)	5 (5)	26 (25)		14 (14)
Problems ($\tilde{x}$=85%*)					
Problems during admission	88 (85)	3 (3)	12 (12)		1 (1)

Percentages are rounded and therefore may not add up to 100.
*Mean of availability of this topic.

Table 4: Description of patient characteristics.

Characteristics	***N (%)***	***Mean (SD)***
Gender		
Male	44 (42)	
Age (years)		73 (15,4)
Marital status		
Married/registered partnership	43 (41)	
Single, never married	17 (16)	
Divorced	12 (12)	
Widowed	21 (30)	
Living situation before admission		
Single	47 (45)	
Living together	32 (31)	
Living in Institution	5 (5)	
Missing	20 (19)	
Residence before admission		
Home	38 (37)	
Hospital	53 (51)	
Nursing/elderly home	8 (8)	
Living at family	2 (2)	
Missing	3 (4,2)	
Length of hospice stay (days)		20 (47,5)*

Percentages are rounded and therefore may not add up to 100.
*Median (IQR), due to not normal distribution.

Table 5: Summarised description of the illness characteristics.
(for a full overview see appendix 2)

Information about admission	**N (%)**
Initating person	
Patient/family	53 (51)
Proffesional	21 (20)
Initiating proffesional	
General practitioner	13 (13)
Other	24 (24)
Goal of admission	
Last resort	100 (96)
Other	4 (4)
Reasons for admission	
Physical symptoms and burdens	82 (79)
Preferred location of passing	17 (16)
Social problems	16 (15)
(Threatening) overcharge personal caregiver	14 (14)
Psychological: cognitive	11 (11)
Other	19 (19)

Information about the illness	**N (%)**
Main diagnoses	
Cancer - Location primary tumour	
Digestive system	25 (24)
Respiration intrathoracally	24 (23)
Other	33 (33)
Organ failure	10 (10)
Neurological problems	2 (2)
Other physical problems**	10 (10)
Cancer - Metastases	
No metastases	37 (36)
Liver	24 (23)
Lungs	21 (20)
Bone	20 (19)
Lymph nodes	15 (14)
Other	41 (41)
Actual co-morbidity's	
Heart and vascular disease	50 (48)
Metabolism and clotting disorders	29 (28)
Lung disease	18 (17)
Urinary tract and reproductive organs	18 (17)
Muscles, connective tissue and joints	12 (12)
Central/peripheral nervous system	10 (10)
None	11 (11)
Other	47 (46)

Information about passing	**N (%)**
Reasons dismission	
Passed away	103 (99)
Transfer to another care institution	1 (1)
Use of end-of-life-care	
Palliative sedation	52 (50)
Euthanasia	5 (5)
Other	38 (37)
Preffered location of dying	
Hospice	65 (63)
Other	4 (4)
Changed preffered location of dying	2 (2)

Information about multidimensionality	**N (%)**
Orientation in time, place, person	57 (55)
Memory problems	25 (24)
Patient worries	14 (14)
Support from closest ones	44 (42)
Support religion	38 (37)

Information about palliative marking	**N (%)**
Date marking palliative phase in days*	27 (157)
Discussed marking palliative phase	65 (63)
Life expectency < 3 months	66 (64
Stage of the illness	
Mainly symptom target palliation	89 (86)
Other	15 (14)
Disease target therapy	
Chemotherapy	13 (13)
Medicamental	12 (12)
Other	18 (18)

Information about problems	**N (%)**
Delirium	30 (29)
Pressure ulcers	24 (23)
Oedema	19 (18)
Bronchopulmonary insufficiency	16 (15)
Reduced awereness	16 (15)
Sub ilieus/passing problems	16 (15)
Urine retention	11 (11)
Existential suffering	11 (11)
Other	63 (62)

Percentages are rounded and therefore may not add up to 100.
*Median (IQR), due to not normal distribution. **As primary problem.

Box 4: Top-10 deployed interventions and top-5 used assessment tools.

Deployed interventions:

1) Pain (n=91)
2) (Prevention of) pressure ulcers (n=59)
3) Dyspnoea (n=29)
4) Pro-active care planning (n=29)
5) Obstipation (n=23)
6) Nausea/vomiting (n=21)
7) Sleeping problems (n=19)
8) Transfer, mobility and posture (n=17)
9) Agitation (n=13)
10) Oedema (n=12)
    Delirium/confusion (n=12)
    Mouth problems (n=12)

Used assessment tools:

1) Karnofsky-score (n=20)
2) USD4D (n=10)
3) OMAHA screening (n=9)
4) Palliative performance scale (n=8)
5) Distress thermometer (n=5)

Appendix 1: Electronic Case Report Form 'patient and care characteristics'

Patient characteristics:

Demographics:

Variable name	Type of variable:	Categories:
Gender	Nominal	- Male - Female
Age	Ratio	N/A
Marital status	Nominal	- Single, never married - Married or domestic partnership - Widowed - Divorced/Separated
Location of admission	Open, quantified to nominal	N/A
Living situation before admission	Open, quantified to nominal	N/A
Residence before admission	Open, quantified to nominal	N/A
Length of hospice stay	Ratio	N/A

Characteristics of the illness:

Variable:	Type of variable	Categories:
Person initiating admission	Open, quantified to nominal	N/A
Initiating professional for admission	Nominal	- General Practitioner - Specialized palliative cancer care nurse - Community nurse - Medical specialist - Specialist geriatric medicine - Otherwise, namely
Elective of acute admission	Nominal	- Elective - Acute
Goal of admission	Nominal	- Last resort - Respite care - Symptom analysis

		- Crisis care - Unknown - Otherwise, namely
Reasons for admission	Nominal	- Physical symptoms and burdens - Psychological: cognitive - Psychological: emotional - Behavioural problems - Social problems - (threatening) overcharge personal caregiver - Existential problems - Preferred location of passing - Otherwise, namely
Reason of dismission	Nominal	- Deceased - Dismission to home - Transfer/admission to another organisation or department - End of support question
Use of end-of-life-care:	Nominal	- Palliative sedation during moment of passing - Acute sedation (e.g. massive bleeding or choking) - Euthanasia - Choose consciously to stop eating/drinking - Other, namely
Patient passed away during admission	Nominal	- Yes - No - Unknown
Preferred location of passing during admission	Nominal	- Home - Hospice - Hospital - Nursing home - Elderly home - At family/friends - Unquestionable for patients and/or close-ones - Unknown - Other, namely
Changed preferred location of passing	Nominal	- Yes - No - Unknown
Main diagnoses	Open, quantified to nominal	N/A
Location primary tumour	Nominal	- Digestive system - Respiration intrathoracally - Female genitals

		- Mamma - Kidneys and urinary tract - Hematology - Male genitals - Skin - Brain/central nervous system - Unknown - Other, namely
Metastases found?	Nominal	- No, no metastases - Liver - Lungs - Pleura - Bone - Peritoneum - Skin - Meningen - Brain - Adrenal - Lymph nodes - Other, namely
Phyiscal dimension:		
Case of organ failure	Open, quantified to nominal	N/A
Neurological problems	Open, quantified to nominal	N/A
Other physical problems	Open, quantified to nominal	N/A
Co-morbidity's	Nominal	- Other malignity - Lung disease - Heart and vascular disease - Gastrointestinal tract - Urinary tract and reproductive organs - Muscles, connective tissue and joints - Central and peripheral nervous system - Metabolism and clotting disorders - Infectious diseases
Psychological dimension:		
Orientation in person, place and time	Nominal	- Yes - No - Unknown
Memory problems	Nominal	- Yes • Short term memory • Long term memory

		• Unknown • Other, namely - No
Social dimension:		
Patients worries about influence of illness on closest ones	Open, quantified to nominal	
Experienced support by closest ones	Nominal	- Yes - No - Unknown
Spiritual dimension:		
Support from religion	Nominal	- Yes • Catholic • Reformed (in Dutch: Hervormd) • Reformed (in Dutch: Gereformeerd) • Protestant • Islam • Jewish • Hindu • Buddhist • Humanistic • Other, namely - No
Other information:		
Number of days from admission till mark palliative phase	Ratio	N/A
Marking palliative phase is discussed with patient	Nominal	- Yes - No - Unknown
Life expectancy at admittance	Open, quantified to nominal	N/A
Stage of illness at admission	Nominal	- Mainly disease target palliation - Mainly symptom target palliation - Terminal palliation - Doubting - Unknown
Which disease target therapy is deployed in the past three months?	Open, quantified to nominal	N/A
Problems during admission, which were an influence in care process (Multiple answers possible)	Nominal	- Infection - Bleeding - Anaemia - Oedema - Bronchopulmonary insufficiency - Pleural fluid

		- Ascites - Sub ileus/ passing problems - Urine retention - Renal insufficiency - Icterus - Stomatitis - Cachexia - Pressure ulcers - Wound - Reduced awareness - Delirium - Coping - Lack of social contacts - Extreme suffering - Other, namely

Experienced symptoms:
Experienced symptoms were operationalized with de four-dimensional Utrecht Symptom Diary (USD4D).

Care characteristics:

Indication for and deploying of (non-)pharmacological interventions:
Deployed (non-)pharmacological interventions were collected as an open variable. Afterwards this variable was categorised and quantified nominal. Indications of interventions were collected open.

Used assessment tools:
Used assessment tools were collected as an open variable. Afterwards this variable was categorised and quantified nominal.

Appendix 2: Description of illness characteristics

A summarised version is provided in table 5 of this paper.

Information about admission	N (%)
Initating person	
Patient/family	53 (51)
Proffesional	21 (20)
Missing	30 (29)
Initiating proffesional	
General practitioner	13 (13)
District Nurse	1 (1)
Medical specialist	8 (8)
Specialist elderly care	1 (1)
Other	14 (14)
Missing	67 (64)
Goal of admission	
Last resort	100 (96)
Respite care	2 (2)
Crisis care	1 (1)
Other	1 (1)
Unknown	2 (2)
Reasons for admission	
Physical symptoms and burdens	82 (79)
Psychological: cognitive	11 (11)
Psychological: emotional	3 (3)
Social problems	16 (15)
(Threatening) overcharge personal caregiver	14 (14)
Existential problems	2 (2)
Preferred location of passing	17 (16)
Other	14 (14)

Information about the illness	N (%)
Main diagnoses	
Cancer - Location primary tumour	
Digestive system	25 (24)
Respiration intrathoracally	24 (23)
Female genitals	6 (6)
Mamma	5 (5)
Kidneys and urinary tract	6 (6)
Hematology	2 (2)
Male genitals	2 (2)
Skin	1 (1)
Brain/central nervous system	6 (6)
Unknown/Space-occupying lesion	3 (3)
Mouth	2 (2)

Information about passing	N (%)
Reasons dismission	
Passed away	103 (99)
Transfer to another care institution	1 (1)
Use of end-of-life-care	
Palliative sedation	52 (50)
Acute sedation	1 (1)
Euthanasia	5 (5)
Other	37 (36)
Missing	8 (8)
Preffered location of dying	
Home	2 (2)
Hospice	65 (63)
Unspeakable for patient/closest ones	2 (2)
Unknown	35 (34)
Changed preffered location of dying	
Yes	2 (2)
No	20 (19)
Unknown	79 (76)
Missing	3 (3)

Information about multidimensionality	N (%)
Orientation in time, place, person	57 (55)
Memory problems	25 (24)
Patient worries	14 (14)
Support from closest ones	44 (42)
Support religion	38 (37)

Information about palliative marking	N (%)
Date marking palliative phase in days*	27 (157)
Discussed marking palliative phase	65 (63)
Life expectency	
≧ 3 months	5 (5)
< 3 months	66 (64)
< 1 month	6 (6)
< 1 week	4 (4)
Unknown	23 (22)
Stage of the illness	
Mainly disease target palliation	2 (2)
Mainly symptom target palliation	89 (86)
Terminal palliation	8 (8)
Doubting	1 (1)

Organ failure			Unknown	4	(4)
Heart failure	8	(8)	Disease target therapy		
Lung failure	2	(2)	Radiotherapy	9	(9)
Neurological problems			Chemotherapy	13	(13)
ALS	1	(1)	Imunotherapy	1	(1)
CVA	1	(1)	Surgery	4	(4)
Other physical problems**	10	(10)	Medicamental	12	(12)
Cancer - Metastases			Other	4	(4)
No metastases	37	(36)			
Liver	24	(23)	**Information about problems**	**N (%)**	
Lungs	21	(20)	Problems during admission		
Pleura	5	(5)	Infection	8	(8)
Bone	20	(19)	Bleeding	5	(5)
Peritoneum	7	(7)	Anemia	3	(3)
Skin	3	(3)	Oedema	19	(18)
Meningen	1	(1)	Bronchopulmonary insufficiency	16	(15)
Brain	9	(9)	Pleural fluid	1	(1)
Adrenal	5	(5)	Sub ilieus/passing problems	16	(15)
Lymph nodes	15	(14)	Ascites	2	(2)
Other	11	(11)	Urine retention	11	(11)
Actual co-morbidity's			Cachexia	2	(2)
Other malignity	8	(8)	Pressure ulcers	24	(23)
Lung disease	18	(17)	Wounds	3	(3)
Heart and vascular disease	50	(48)	Reduced awereness	16	(15)
Gastrointestinal tract	5	(5)	Delirium	30	(29)
Urinary tract and reproductive organs	18	(17)	Coping	3	(3)
Muscles, connective tissue and joints	12	(12)	Lack of social contacts	2	(2)
Central/peripheral nervous system	10	(10)	Existential suffering	11	(11)
Metabolism and clotting disorders	29	(28)	Other	34	(33)
Infection diseases	2	(2)			
None	11	(11)			
Other	32	(31)			

Percentages are rounded and therefore may not add up to 100.
*Median (IQR), due to not normal distribution. **As primary problem.