

Expectations of future hospice patients: a qualitative exploration.

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SUMMARY

Background: Inpatient Hospice Care (HC) in the Netherlands is available for patients with life expectancies <3months. Insight in expectations of patients regarding HC is needed to make HC more patient-needs driven and future-oriented. A theoretical framework to evaluate expectations of patients, including structure, process and outcome of care (SPO) was used to explore future hospice patient's expectations.

Research Question: What are the expectations of future hospice patients regarding structure, process and outcome of care in a hospice in Dutch society?

Methods: A qualitative study, using semi-structured interviews and thematic analysis, is performed in the Netherlands from Jan 2018-June 2018. A convenience sample of eleven patients with a life-limiting disease and two patient representatives was drawn.

Results: Hospice admission is only expected when the burden is unbearable to die at home. Structure of care: patients expected a place with a homely atmosphere where you can continue the life you lived at home as much as possible, together with your family. Process of care: participants expected empathic and professional caregivers, capable of providing appropriate care. The General Practitioner is expected to stay involved in the care process, because of the mutual trust. Outcome of care: medical and daily care should be provided by competent professionals. Volunteers should provide supportive care. All caregivers should be competent in providing a listening ear and 'being there' for patients. Social care and spiritual care are mainly expected to be private matters, unless it is requested.

Conclusion and recommendations: Future hospice patients have high expectations about HC regarding SPO. Perceptions about HC in the public domain should be nuanced responding to these expectations and information provision about HC should be improved. Then, expectations could be met and HC could be more patient-needs driven and future-oriented.

Key Words: Hospice Care, Hospices, Hospice and Palliative Care Nursing, Expectations.

SAMENVATTING

Achtergrond: Hospice zorg (HZ) is in Nederland beschikbaar voor patiënten met een levensverwachting van <3 maanden. Om HZ patiëntgericht en toekomstbestendig te maken is inzicht in de verwachtingen van patiënten omtrent HZ nodig. Een theoretisch kader om de verwachtingen van patiënten te evalueren middels structuur, proces en uitkomst van zorg (SPU) is gebruikt om inzicht te krijgen in de verwachtingen van toekomstige hospice patiënten.

Onderzoeksvraag: Wat zijn de verwachtingen van toekomstige hospice patiënten omtrent structuur, proces en uitkomst van zorg in een Nederlands hospice?

Methode: Een kwalitatieve studie, met semigestructureerde interviews, en een thematische analyse, is uitgevoerd in Nederland van Jan 2018-Juni 2018. De steekproef bestond uit elf patiënten met een levensbeperkende ziekte en twee patiëntvertegenwoordigers.

Resultaten: Opname in een hospice wordt alleen verwacht wanneer het ondraaglijk is om thuis te sterven. Structuur: Men verwacht een huiselijke plek waar men het leven kan blijven leiden dat men thuis leefde, samen met familie. Proces: participanten verwachten empathische en betrouwbare zorgverleners, die in staat zijn om passende zorg te leveren. De eigen huisarts wordt verwacht betrokken te blijven in het proces, vanwege de vertrouwensband. Uitkomst: Medische en dagelijkse zorg zou door bekwame professionals geleverd moeten worden. Vrijwilligers zouden ondersteunende zorg moeten leveren. Alle zorgverleners moeten bekwaam zijn in het bieden van een luisterend oor en het 'er zijn'. Sociale en spirituele zorg worden verwacht privéaangelegenheden te zijn, tenzij er om hulp gevraagd wordt.

Conclusies en aanbevelingen: Toekomstige hospice patiënten hebben hoge verwachtingen over HZ met betrekking tot SPU. De informatievoorziening over HZ zou verbeterd moeten worden en de beeldvorming over HZ zou genuanceerd moeten worden. Dan zou aan de verwachtingen voldaan kunnen worden en zou HZ meer patiëntgericht en toekomstbestendig kunnen worden.

Trefwoorden: Hospice Zorg, Hospices, Palliatieve Zorg, Verwachtingen.

INTRODUCTION

Hospice care (HC) developed into a wide variety of initiatives worldwide¹ since the first hospice was founded in 1967.² HC is multidimensional care, aiming to optimize the quality of life of patients and their families during their dying months, by minimizing suffering in the physical, psychological, social and spiritual dimension.³⁻⁶ Suffering consists of components from all dimensions, influencing each other and together forming a “total pain” experience, specific for each patient.⁷ Treatment of hospice patients is therefore complex⁷ and a multi-professional approach of co-operation and deliberation^{8,9} with a multidimensional view⁷ is required to address hospice patients’ needs. In the Netherlands, the number of inpatient hospices increased from 86 in 2007,¹⁰ to 292 in 2014.^{11,12} Reasons for admission in a Dutch hospice are last resort, respite-care, crises and day-care,^{4,13} available for patients with life expectancies less than three months.³ Three types of hospices developed in the Netherlands: Volunteer-driven hospices (VDH), High-Care-Hospices (HCH) and Palliative Care Units (PCU).^{11,14} VDH are standalone hospices¹¹ where trained volunteers provide daily care,^{14,15} supported by district nurses^{3,4} and patient’s own general practitioners (GPs).^{3,4} HCH are standalone,¹¹ professional-driven hospices^{14,15} meaning patient’s own GPs, hospice GPs or medical specialists provide medical care.^{3,4} Nurses are available 24/7 to provide daily care, supported by trained volunteers.^{3,4} PCU are professional-driven^{14,15} units inside nursing homes.¹¹

Due to HC’s short history, research in HC is scarce.^{1,14} Furthermore, research in HC from around the world cannot be generalized to the Netherlands, due to differences in health-care systems.¹⁴ The little amount of literature that is available shows that terminally ill patients want to stay in control of life, care and things related to loved ones.^{16,17} However, this studies focused mainly on elderly people’s perspectives^{18,19} and terminally ill patients’ family members.²⁰ Studies with terminally ill patients rarely focus on their perspectives,²¹ and seldom are performed in HC.¹⁴ Recent Dutch research showed that 68% of Dutch people preferred to die at home and 27% in a hospice.²² Realising the preferred place of death is seen as an important quality-indicator for ‘end-of-life care’.²³ Another Dutch study explored perceptions on the place to die. Reasons to die in a hospice are; there is no spouse able to care for the patient at home, the availability of specialised care, the opinion of family-members, familiarity with HC.²¹ Although we know how many people want to die in HC²² and why they want to die in HC,²¹ no insight in needs and visions of patients about HC is available. To make HC more patient-needs driven and future-oriented it is necessary to gain this insight.^{4,21,24} Therefore the project ‘**H**ospicezorg die **P**assend is en de **E**igen wens van mensen in de palliatieve terminale fase **V**olgt (HOPEVOL)’,¹⁴ aiming ‘to give shape in hospice care as demand-oriented, timely and future-oriented, thereby optimizing quality of life and dying of people in their last phase of life at the location of their desire’ is launched.

This study is conducted in the second phase (Figure 1) of the HOPEVOL-project. Expectations can be viewed as the major determinant for patient satisfaction with health care²⁵ and are explained as: “a strong believe that something will happen or be the case.”²⁵ Geurts et al. provided a framework (Figure 2) for understanding patient expectations²⁵ consisting of three elements to evaluate expectations of patients, including structure, process and outcome of care (SPO), further specified in Table 1.^{25,26} These expectations can be divided into value expectations and predicted expectations.²⁵ Value expectations represent ideals and predicted expectations are the more realistic expectations.²⁵ Value expectations can be divided in three different expectations; ideal expectations such as hope and desires, necessities like what is perceived to be needed and normative expectations, that what should or ought to happen. Awareness of patients’ met and unmet expectations enables staff to understand patients’ perspectives,²⁷ and thus contributes to demand-oriented care. HC should respond to expectations on SPO, aiming to make HC future-oriented. Therefore, this framework²⁵ is used as a theoretical framework for this study to gain insight in expectations of future hospice patients supporting the amelioration of HC.

RESEARCH QUESTION

What are the expectations of future hospice patients regarding structure, process and outcome of care in a hospice in Dutch society?

METHOD

Design

A generic qualitative exploratory design was used.²⁸ This design was appropriate to gain first insights into expectations of future hospice patients, and to understand their perspectives.^{29–31} Aiming to give a description of expectations using thematic analysis following an iterative process, a generic approach was appropriate.^{28,32} For this report the COnsolidated criteria for REporting Qualitative studies (COREQ)³³ were used.

Population & domain

A convenience sample was drawn of patients having a life-limiting disease, receiving palliative care according to the continuum of palliative care (Figure 3).³⁴ Patients with a life expectancy of less than one year were recruited through GPs, hospice waiting lists and home care organisations in the Netherlands. To identify patients with an estimated life expectancy of less than one year, caregivers used the ‘surprise’ question: ‘Would I be surprised if this patient died in the next year?’^{5,35} If the answer was ‘no’ patients were eligible for enrolment. In addition representatives of patients for whom HC may be appropriate in the future were recruited from the patient-and-family-board of the Consortium Septet, which is a

regional partnership for palliative care in the Netherlands.³⁶ Because patient representatives are used to provide a 'voice' for patients about healthcare problems, they could provide a more abstract view on the subject.³⁷

Data collection

Semi-structured in-depth face-to-face interviews were conducted by the researcher (RB) between March 2018 and June 2018.^{31,38} A topic guide based on Geurts' framework²⁵ (Table 2) was used and tested in a pilot interview.^{29,38} This topic guide was revised during the iterative process of data collection and analysis.^{38,39} Each interview started with a general question: 'What is your image of a hospice?', to ease participants turning them into more fluent talkers.³⁸ Next, RB complemented participants' image with information about HC. Key-notes were used to record feelings and thoughts of RB.⁴⁰ Different probing techniques like remaining silent, echoing, verbal agreement and asking participants to elaborate more about a topic, were used to gain insight in expectations of participants.³⁹ During the interviews, data were orally summarized and paraphrased, so participants were allowed to correct errors or question interpretations, as a member check.²⁸ Data collection continued until data saturation was reached.⁴¹

Procedures

Patients were first identified and approached by their caregivers before the researcher contacted them. Potential respondents received succinct information about the study by phone and mail. When potential respondents agreed to be interviewed, an appointment was made in the participants' preferred setting. The informed consent procedure was followed before the interviews started. Interviews were audio-recorded. After the interviews, a case report form was filled in to collect demographic data and emotional support by a trained hospice nurse was offered to all participants.

Data analysis

Collection and analysis of data was an iterative process using thematic analysis to clarify expectations of future hospice patients.^{28,42,43} Two members of the research team, a novice researcher (RB) and an experienced qualitative researcher (MvK), independently carried out the six phases of thematic analysis. Researcher triangulation was used ensuring validity and reliability.^{31,41} Firstly, interviews were transcribed by RB and transcripts were read and re-read.⁴² Secondly, initial codes were generated. NVivo11⁴⁴ was used to facilitate the coding process.⁴² The process of coding and developing themes was done in groups of three interviews⁴². After every three interviews RB and MvK consulted each other, to reach consensus. If there was no consensus, a senior qualitative researcher (EdG) was consulted. Thirdly, codes were collected into potential themes. Fourthly, themes were reviewed by checking if themes worked in relation to the coded extracts (level 1) and the entire data set

(level 2).⁴² Fifthly, clear definitions and names for each theme were defined.⁴² Sixthly, examples were selected and final analysis took place and the research question and literature were related to the themes.⁴² To ensure no thoughts of the researchers were lost and to ensure reflection on patterns in the data, memos were used throughout analysis.³¹ Used quotes to clarify the results were translated by RB and checked by MvK. Peer-feedback was given by the research team to enhance the quality of the process and the results.³¹

Ethical Issues

This study was conducted according to the principles of the Declaration of Helsinki.⁴⁵ The research protocol was approved by the Medical Research Ethics Committee (reference-number 18-098/C) of the University Medical Centre of Utrecht. This research fell outside the Medical Research Involving Human Subjects Act (WMO).⁴⁶ All participants gave permission to their caregivers to be contacted by the research team, according to the Medical Treatment Contracts Act (WGBO).⁴⁷ All participants were informed about possible benefits, like discussing their situation with a friendly and impartial person and risks such as emotional distress. All participants were informed that they could always stop the interview or refuse a question. Informed consent was obtained before the interviews took place.^{29,31}

RESULTS

Fifteen participants were included for this study. Two patients died before the interview took place. Seven men and six women participated in the interviews, eleven had a life-limiting disease. Two participants wanted to do the interview in the presence of a relative. Two other participants wanted to have a joint interview. All participants were interviewed in their home, except for one who was interviewed in a neutral room. Median age was 76 years (range 34-93). One participant was from Surinam origin, the other participants were Dutch. Five participants were atheist, seven were Christian and one was Hindu. Other demographic data are shown in Table 3.

Interviews lasted between 24 minutes and 84 minutes (median 52 minutes).

First the results were divided into the SPO framework.²⁵ Within this framework, the main themes that derived were identified. In 'structure of care' two themes were identified, namely: atmosphere and living your own life. In 'process of care' the themes attitude of caregivers and General Practitioner derived. 'Outcome of care' includes the themes physical care, psychological care, social care and spiritual care. Table 4 gives an overview of the main results regarding SPO. Perspectives on HC was seen as an overall theme, not being

included into the SPO framework.²⁵ Details of expectations are further illustrated by quotes in Table 5 (Q-references in the text refer to specific quotes in Table 5).

Perspectives on HC

Participants were not aware of the different reasons for admittance to a hospice, and saw a hospice as the end station, a place to die (Q01). Most participants stated they only want to be admitted when dying at home is unbearable, and taking care of them at home would be too hard for their family. In addition, more than half of the participants expected to be in a very poor condition when admitted (Q02), like being dependent on care and not being able to walk, talk or eat. One participant had never heard about a hospice before.

Structure of care

Only value expectations were found regarding 'structure of care' and these were expressed in ideals, necessity and normative expectations.

Atmosphere

A homely atmosphere in a hospice was perceived as an important necessity. In contrast to hospitals, hospices should have a comforting, safe and cosy atmosphere (Q03). A small-scaled building, with enough privacy, e.g. an individual spacious room for intimate moments where you can retreat with your family, supports a safe and secure atmosphere. Participants preferred this room to be designed like a living room, to make them feel like home. Something else that should contribute to a homely atmosphere is the possibility to bring personal belongings such as remembrances for home, family-pictures and other memories of loved ones (Q04). Half of the participants also desired to be laid out in the hospice, so family could say goodbye in a homely atmosphere.

Living your own life

All participants stated the importance of continuing the life they lived at home as much as possible when admitted to a hospice. Loved ones should be able to visit any time they want, like they were used to at home, therefore the absence of visiting hours (Q05) and a private room (Q06) are crucial. Relatives spending the night in the hospice was expected to be essential, because most participants disliked the idea of being alone when close to dying. In addition, one participant hoped he could take his pet to the hospice, because it functions as a comforter. Loved ones staying for dinner was also expected to be important by most participants, as dinner was stated as an intimate daily moment, preferably enjoying a familiar meal (Q07). To enjoy the end-of-life period as much as possible, distraction was expected to be a key point. According to most participants, patients should have freedom in doing what they like in their last phase of life just as they did at home (Q08), such as watching television, surfing the internet and listening to music. More than half of the participants expected to find

distraction by going outside or to see a garden from their open window, which gives the opportunity to feel the air and sun and to listen to the wind or sounds of life outside (Q09).

Process of care

Only value expectations were found regarding 'process of care' and these were expressed in ideals, necessity and normative expectations.

Attitude of caregivers

According to all participants, hospice caregivers should have a calling to do the vocation to care for dying people (Q10). Participants expected empathy and respect to be the most important qualities for all caregivers, contradictory to a hospital or nursing home where caregivers were considered as less friendly and impatient. All participants stated hospice caregivers should be available at any time, providing appropriate care by discussing patients' needs and wishes. Decisiveness, reliability and competence were qualities specifically attributed to professional caregivers (Q11). In addition, volunteers were expected to be trained and to complement the professionals (Q12).

General Practitioner

Almost all participants expected their GP could still have a significant role in end-of-life care when admitted to a hospice, because of the highly appreciated mutual trust (Q13). Because the GP was expected to know the patient best, participants desired them to discuss important choices concerning end-of-life care with, like euthanasia requests or palliative sedation. Physicians specialized in palliative care should deliver the required medical care, according to most participants. Almost half of the participants stated that these physicians could provide more specific care than their GP (Q14).

Outcome of care

Only value expectations were found regarding 'outcome of care' and these were expressed in ideals, necessity and normative expectations.

Physical Care

Participants mainly expected physical complaints such as pain, dyspnoea and reduced ability of self-care. Professionals should provide medical care like medication and wound care, and daily care according to most participants. Besides, professionals should respect and fulfil a patient's euthanasia request according to some participants, otherwise they would rather die somewhere else. Volunteers were perceived to be needed to provide supportive care, e.g. polishing nails (Q15).

Psychological Care

Some participants expected psychological complaints such as anxiety, gloom or amnesia, although most participants did not expect psychological complaints when admitted to a

hospice at all. Professionals were perceived to provide conversations to relieve psychological burden and to comfort patients when feeling lost (Q16). Volunteers should have a supporting role by providing a listening ear and especially 'being there' when needed, which is thought to be of inestimable value when in psychological need (Q17).

Social Care

More than half of the participants stated social care to be a private matter with their loved ones, where caregivers should not interfere unless it is asked for. Some participants did not expect to need social care at all, and stated that caregivers could not be of any help according to this (Q18). Participants who did expect social care pointed out that volunteers should accompany patients and their families phase on request, especially for practical help (Q19).

Spiritual Care

Talking about life and death is perceived to be very comfortable by almost all participants. All religious participants preferred a spiritual worker or religious volunteer to provide spiritual care, such as having conversations, carrying out rituals and providing a listening ear (Q20). All non-religious participants stated that spiritual care is a private occasion, provided only by loved ones unless it is requested. When spiritual care is requested, professionals and volunteers could 'be there' and provide a listening ear.

DISCUSSION

This study aimed to explore expectations of future hospice patients regarding HC. Patients with a life-limiting disease and their representatives expected admittance in a hospice only when dying at home is unbearable. For all components of the SPO framework,²⁵ only value expectations were found. Regarding 'structure of care', participants expected a place with a homely atmosphere where you can continue the life you lived as much as possible, together with your family. In 'process of care', participants expected empathic and professional caregivers, able to provide appropriate care. Also, it is expected to be advantageous to have their own General Practitioner staying involved in the care process, because of the mutual trust. In 'outcome of care', medical and daily care should be provided by professionals, where volunteers should provide supportive care. All caregivers should be competent in providing a listening ear and in 'being there' for patients. Social care and spiritual care are mainly expected to be private matters.

Most previous research in HC is done with elderly patients, relatives or caregivers instead of palliative care patients. Dying patients appreciate to participate in research, considering their contribution as important, especially when it could help others.⁴⁸ In addition, most research in HC is done with oncology patients. The participants in this study cover a large distribution of

characteristics, providing maximum variation in phases of palliation, diseases and experiences with HC which is an important strength of this study. A broad insight into expectations is therefore shown,⁴¹ complemented with the more abstract view of patient representatives.³⁷ We cannot assume that the emerged themes of this study would have arisen from a sample in another country, because of worldwide differences in HC. Since data saturation was reached, we are under the impression that many themes will also emerge with another sample in the Netherlands. The use of researcher triangulation,^{31,41} member checks²⁸ and memo's during the entire process of data collection and analysis³¹ strengthens this research. The iterative process enabled adding new insights into the topic guide. However, some limitations should be made. Because of palliative care patients' vulnerability, inclusion of participants for this study was difficult, resulting in a convenience sample, where a purposeful sample was aimed for. Including more younger patients could have contributed to the current results. However, since the average age of hospice patients is 71.7 years,⁴⁹ the sample is a representation of future hospice patients.

Existing literature shows that for older patients with a life-limiting disease¹⁹ and according to terminally ill patients' surviving relatives²² it is important to feel at home in the palliative phase.^{19,22} Besides, oncology patients identified an unfriendly and clinical environment as one of the main perceived worries of HC.⁵⁰ Our study found that patients with a life-limiting disease expected that hospices have homely and comforting atmospheres, where you can feel safe. This expectation corresponds with mission- and vision statements of hospices in the Netherlands, where atmosphere is defined in terms like homely and comfortable.⁵¹ Furthermore, the continuation of daily life is very important^{21,52,53} for terminally ill patients,²¹ older patients⁵³ and cancer patients receiving palliative care.⁵² Freedom, privacy and the absence of visiting hours are seen as important components in this matter.²¹ Therefore, hospice caregivers try to give patients control of daily activities.⁵⁴ From the results of the interviews it appears that patients expected to be able to continue daily life and to stay in control of daily activities. Consistent to literature,²¹ patients did not expect visiting hours and valued privacy and freedom for themselves and their families. This also corresponds with mission- and vision statements of hospices in the Netherlands, where staff's respect for patients' privacy was mentioned by all hospices.⁵¹ Caregivers' attitude in the palliative phase is also essential for palliative care patients, and is expected to be personal and that the patient is taken serious.⁵⁵ The expectations of patients in this study can be seen as very similar, although they add that they also expected their caregivers to be empathic and competent. Moreover, patients explicitly want their own GP to be involved during the admission in a hospice, due to the mutual trust. In another study hospice staff members also confirmed that palliative care patients saw the loss of their own health care provider as a

major concern.⁵⁴ In a study with oncology outpatients there were three important perceived benefits of HC, which were good pain management, the availability of medical care and to have medical staff on call.⁵⁰ This study endorses these findings. Patients had the expectation that medical care would be always available, delivered by medical staff. This medical care is expected to be good, without exception. Next to the medical care, patients expected that all caregivers would have conversations with them, but especially that volunteers could provide a listening ear and to just 'be there'. This is also defined as the essence of the tasks of a volunteer, according to the literature.⁵⁶ The national Quality Framework Palliative Care (2017)⁵⁷ sets standards for palliative care in general. The importance to mark the palliative phase on time, so proactive care planning could be provided to minimize suffering for palliative care patients is stated in this framework.⁵⁷ This is also stated in the definition of palliative care which states the importance of an early identification of multidimensional problems.⁵⁷ The expectation to go to the hospice only then when it is unbearable to die at home gives a friction because then it is too late to offer a temporary admission and to provide this proactive care because all admissions would be in times of crisis. Therefore, it is important to nuance the perceptions in the public domain in response to the results of this study and to give respite care and temporary admissions more publicity. It is important to make a distinction between value and predicted expectations (Figure 2), especially in clinical practice.²⁵ Participants who had more knowledge about HC could provide more precise expectations and were able to provide predicted expectations. However, most participants had very high expectations of HC and provided mainly value expectations. Therefore, information provision to care providers in primary and secondary care should be improved so future hospice patient's understanding of HC could be enhanced and expectations can be met.

To conclude, future hospice patients have high expectations about HC regarding SPO. Perceptions about HC in the public domain should be nuanced responding to these expectations and information provision about HC should be improved. Then, expectations could be met and HC could be more patient-needs driven and future-oriented.

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TABLES

Table 1 – Elements for understanding expectations²⁵

Component	Explanation	Examples
Structure	Care setting	Building characteristics Availability of facilities
Process	Patient's movement through the care process and services provided during the care process	Provider characteristics
Outcome	Effects of healthcare	Effects on patient's health Effects on quality of life

Table 2 – Topic guide for the interviews

Topics

Structure

Facilities
Accessibility
Daily structure

Process

Attitude
Type of caregiver
General Practitioner
Availability

Outcome

Physical care
Psychological care
Social care
Spiritual care

Table 3 – Demographic Characteristics

	Age	Marital status	Profession (former)	Residential area	Disease	Preferred location for care	Preferred location to die	Type of palliation	Knowledge of Hospice Care
R01	69	W	Other	Rural	Cancer	Hospice	Hospice	SO	Moderate
R02	57	M	Health Care	Rural	Cancer	Home	Home	DP	Moderate
R03	78	D	Other	Rural	CNS	Home	None	SO	Poor
R04	34	S	Other	Rural	CNS	Home	Hospice	DO	Poor
R05	68	M	Health Care	Rural	CNS	Home	Home	DO/SO	Poor
R06	84	W	Other	Suburban	Cancer	Hospice	Hospice	SO	Moderate
R07*	78	M	Health Care	Urban	/	Home	Home	/	Much
R08	77	M	Other	Urban	Heart failure	Home	Home	SO	None
R09	69	S	Other	Rural	Cancer	Home	Hospice	SO	Poor
R10*	76	M	Other	Suburban	/	Home	Home	/	Much
R11	72	W	Health Care	Rural	Heart failure	Home	Home	DO	Much
R12	89	M	Other	Urban	Heart failure	Home	Home	SO	Poor
R13	93	M	Health Care	Urban	Heart failure	Home	Home	SO	Poor

* = patient representative; W=Widow(er); M=Married; D=Divorced; S=Single; CNS = Central Nervous System; SO = Symptom oriented; DP = Dying Phase; DO = Disease oriented

Table 4 – Results regarding structure, process and outcome of care.

Component	Explanation	Main expectations
Structure	Care setting	Homely atmosphere Absence of visiting hours Distraction
Process	Patient's movement through the care process and services provided during the care process	Empathic and respectful caregivers Reliable professionals Supportive volunteers Mutual trust with own GP in care process
Outcome	Effects of healthcare	Medical and daily care by professionals Volunteers 'being there' No social and spiritual care, unless requested

Table 5 - Quotes

Framework	Themes	Quotes
	Perspectives on Hospice Care	Q01: "In my opinion a hospice is only intended for the final part. When you are lost, when there is no hope left. You are just waiting for death." (R03)
		Q02: "I will not go to a hospice for fun, so I have to be too far gone to go there." (R12)
<u>Structure of care</u>	Atmosphere	Q03: "And there you see very big differences between a hospital or a hospice that accompanies the final phase. There is, well, at least 500% difference between them ... I think the hospital is very cold, very, cool. And you preferably need to leave as fast as you can, because they need a room. While a hospice is, yes, very different" (R01)
		Q04: "There is room for a picture and some small personal stuff you could put there, so you keep a piece of yourself with you. Yes, it sounds safe, it sounds good, let me put it like that." (R01)
	Living your own life	Q05: "You should not have visiting hours. Visitors should come whenever they want ... But, let me put it differently. Visitors, that is a different case. You should adjust to one another. My kids, they should walk right in, they should not make an appointment ... Just like home actually." (R02)
		Q06: "I would not want to share my despair and my emotions with others. I want to keep them for myself and for my loved ones. That is why a private room is very important to me." (R07)
		Q07: (I: "And do you think it is important that your family could have dinner with you?") "Yes, imagine when you are lying there, especially then it is very important, because it is the daily life we always lived, it should continue as long as possible." (R02)
		Q08: "That in a reasonable way, that respect is shown for the life you lived before, which you really want to continue as much as possible until you die." (R11)

Q10: "To hear sounds, also from outside, to know that life, that life continues. You are facing death but it is good to hear life at the same time." (R07)

Process of care Attitude of caregivers Q10: "You will accompany people at the end of their life which won't always be easy. So you will automatically have a sort of professionalism to ease those people as much as possible, it comes from within you, or else you would not work there. Well, that is the thing that appeals to me in a hospice." (R01)

Q11: "You have a lot of well-intentioned volunteers. Of course, great, wonderful people. But what do they know? ... There is a big difference with professionals for me, very big!" (R11)

Q12: "I think the professionals will experience a time pressure, because it all depends on money. And the volunteers they got the time and they like it, it beautifully complements each other." (R09)

General Practitioner Q13: "He comes here every week. Sometimes twice a week. And then we talk about things ... And because you have that bond with your General Practitioner, that connection, that has to stay!" (R02)

Q14: "A specialized physician knows more than a GP. He could advise you, your husband, your children. A General Practitioner could do this as well, but a specialized physician is better at it." (R07)

Outcome of care Physical Care Q15: "It depends, in my case, I am already disabled of course. So I would prefer a nurse providing care instead of a volunteer ... If it considers medical care, and daily care like dressing up. A volunteer should comb your hair or polish your nails. I do not think a volunteer is educated to provide daily care like dressing up and that sort of care." (R04)

Psychological Care Q16: "That you can talk with someone or other things that could settle you down, I do not know. I guess." (R05)

Q17: (I: "And could you imagine in the last phase that you would like support for psychological complaints?") "Probably. I have it already. Not that I am unstable, I do not think so, but. It is very pleasant to pour out your heart." (R03) ... (I: "And if you would want support with psychological complaints, what kind of caregiver would you expect?") "A listening ear." (R03)

Social Care Q18: "I think it has to come from within oneself. Look, when I have a relationship with you. Emotionally another person cannot help me with that, nor help you to say goodbye to each other. I think it has to come from within oneself." (R06)

Q19: "Well looking at the funeral, if my daughter needs help, she knows everything, but you never know. That they accompany her, yes, take care of her. I think that is important." (R05) (I: "That they will take care of your children?") (Patient is emotional while looking at a picture of her family) "Especially my grandchildren." (R05)

Spiritual Care Q20: "But, what you do have with fellow believers, with them you could talk easier at the moment you are in mental need, than when it is not the case. Because then there is a sort of a blockage." (R06)

FIGURES

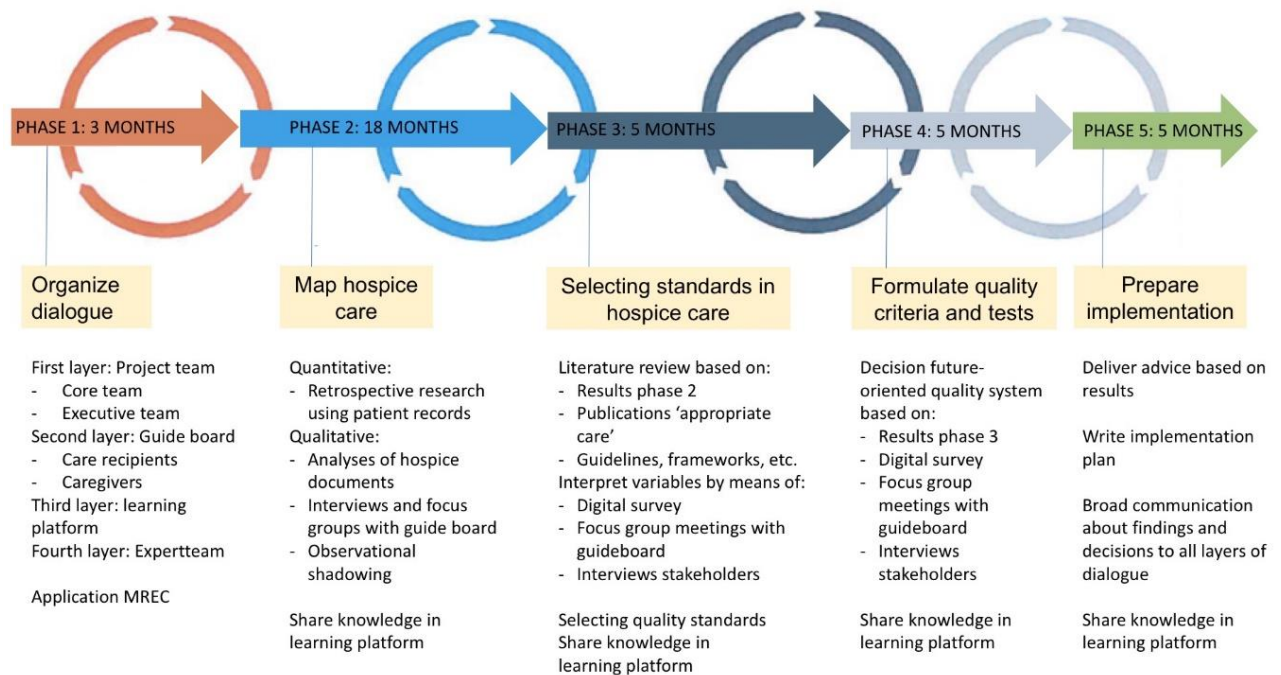


Figure 1 – Phases of the HOPEVOL Project.¹⁴

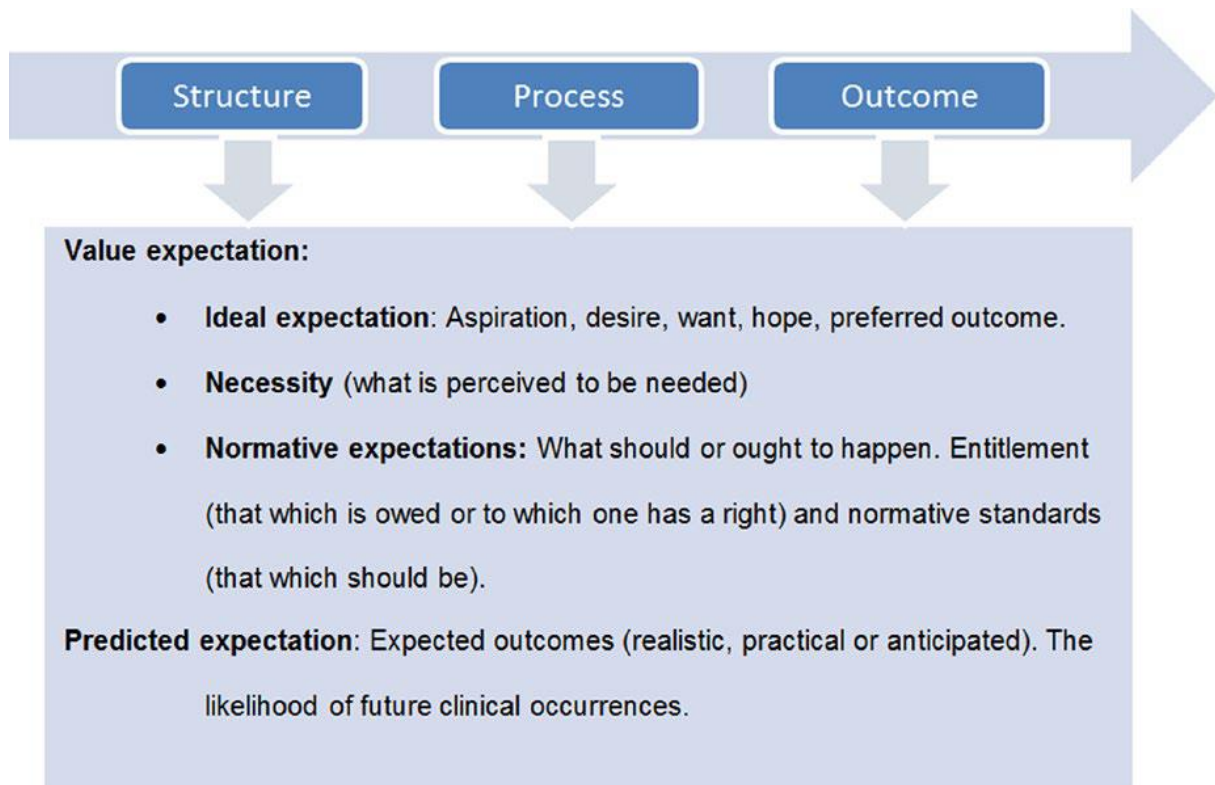
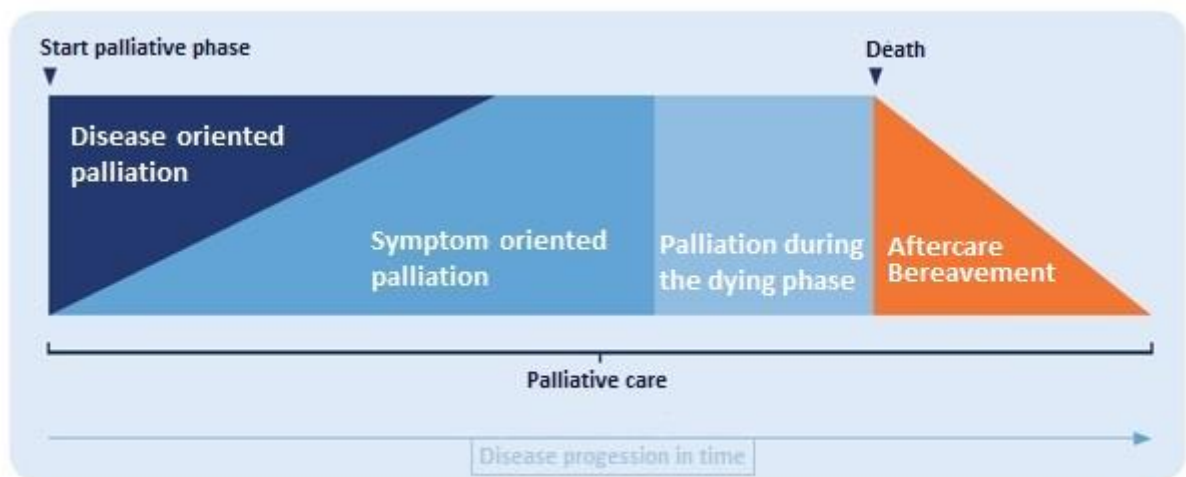


Figure 2 – Framework for understanding expectations.²⁵



Adapted from Lynn, 2003

Figure 3 – Continuum of palliative care³⁴