

**The practices and attitudes of nurses on appropriate hospice-care:
an explanatory mixed-methods study**

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Summary

Title: The practices and attitudes of nurses on appropriate hospice-care: an explanatory mixed-methods study.

Background: Appropriate hospice-care arises from a close collaboration of care and treatment of the problems, complaints, wishes and needs of patients in the four dimensions of multidimensional care. Dutch hospices adopt the core characteristics of hospice-care in different ways. The extent to which appropriate hospice-care is given depends on caregivers' attitudes. Appropriate hospice-care is operationalized into six key-concepts: individual care-plan, quality of life, support of family-caregivers, care relationships, shared decision-making and preferred location of death.

Aim: This study aimed to explore the practices and attitudes towards appropriate hospice-care of nurses working in Dutch hospices.

Method: An explanatory mixed method study with a quantitative-qualitative sequential design was performed from January 23, 2017 to June 30, 2017. A quantitative survey was performed to study appropriate care in daily practice. In addition, four focus-groups were performed to study nurses' attitudes regarding appropriate care.

Results: Within the survey, 275 nurses participated, 19 nurses participated in focus-groups. A majority of the nurses indicated that practices, regarding the six key concepts, were in accordance with appropriate care. All six key-concepts were acknowledged and nuanced by nurses' attitudes as indicators for appropriate care. Nurses' competences and the organizational structure within a hospice are determinative for the nurses' daily practices, even when this is in violation with the nurses' attitudes.

Conclusion: Despite the positive attitudes regarding the six key-concepts, nurses are not able to apply appropriate hospice care in daily practice today. To achieve this, more knowledge among nurses and policymakers about ways in which appropriate hospice care can be implemented and delivered will be necessary.

Recommendation: Further research is needed to discover the perspectives of professional-caregivers, patients and family-caregivers, regarding appropriate hospice-care.

Keywords: Palliative care, multidimensional care, patient-centered care, appropriate hospice-care.

Samenvatting

Titel: De werkwijzen en attitudes van verpleegkundigen in relatie tot passende hospicezorg: een verklarende mixed-methods studie.

Achtergrond: Passende hospicezorg komt voort uit integratie van zorg en behandeling van problemen, klachten, wensen en behoeften van patiënten in de vier dimensies van multidimensionale zorg. Nederlandse hospices implementeren de kernelementen van hospicezorg op verschillende manieren. De mate waarin passende hospicezorg wordt verleend hangt af van de attitude van de zorgverleners. Passende hospicezorg is geoperationaliseerd in zes kernwaarden: individueel zorgplan, kwaliteit van leven, ondersteuning van naasten, mantelzorgrelaties, gedeelde besluitvorming en voorkeurslocatie van overlijden.

Doel: Dit onderzoek heeft als doel de werkwijzen en attitudes, in relatie tot passende hospicezorg, van Nederlandse verpleegkundigen te verkennen.

Methode: Een verklarende mixed-methods studie met een kwantitatief-kwalitatief sequentieel ontwerp werd uitgevoerd van 23 januari 2017 tot 30 juni 2017. Een survey is afgenomen om werkwijzen met betrekking tot passende zorg in de dagelijkse praktijk te achterhalen. Vier focusgroepen zijn uitgevoerd om attitudes van verpleegkundigen te achterhalen.

Resultaten: Binnen de survey hebben 275 verpleegkundigen geparticipeerd, 19 verpleegkundigen hebben geparticipeerd in focusgroepen. Een meerderheid van de verpleegkundigen heeft aangegeven dat de hedendaagse werkwijzen altijd of meestal in overeenstemming zijn met passende hospicezorg. Alle zes de kernwaarden werden erkend en genuanceerd als indicatoren voor passende zorg. De competenties van verpleegkundigen en de organisatiestructuur binnen een hospice zijn bepalend voor de werkwijzen van verpleegkundigen, zelfs als dit in strijd is met de attitude van de verpleegkundigen.

Conclusie: Ondanks de positieve attitudes, zijn verpleegkundigen niet in staat om passende hospicezorg toe te passen in dagelijkse werkwijzen. Om dit te bereiken, zal meer kennis nodig zijn over manieren waarop passende hospicezorg geïmplementeerd en geleverd kan worden.

Aanbevelingen: Verder onderzoek zal nodig zijn om de perspectieven van zorgverleners, patiënten en families op passende hospicezorg te achterhalen.

Zoekwoorden: Palliatieve zorg, multidimensionale zorg, patiëntgerichte zorg, passende hospice zorg.

Introduction

In 2011, more than 19 million adults in the world were in need of palliative care (PC).¹ In the Netherlands, 148.898 people deceased in 2016.² In 2014, 141.245 people died a non-sudden death and these people could benefit from palliative or hospice-care during the last months of their end-of-life period.³

“PC is 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

There are two levels of PC worldwide, general palliative care (GPC) and specialized palliative care (SPC).⁵ GPC is when involved caregivers are not specialized in delivering PC, e.g. general practitioners and district-nurses. SPC is when involved caregivers are specifically trained in delivering PC. In the Netherlands, GPC and SPC can be delivered in a hospice.⁶ However, PC is not a medical speciality in the Netherlands, that is why it is mostly delivered by generalists.⁶ Hospice-care is multidimensional care (MDC), provided by a multi-professional team of formal and informal caregivers.⁶ MDC aims to optimize quality of life during the last months of patients' life and their loved ones by decreasing physical, psychological, social and spiritual suffering.⁷

There are 153 self-contained hospices for adults and the elderly in the Netherlands, of which 83 are professional driven hospices (PDH) and 70 are voluntary driven hospices (VDH).^{7,8} PDH provide specialized PC by a constantly present nursing staff, supported by trained volunteers. Medical care is provided by a physician who is specialized in PC, and/or the patient's general practitioner. VDH provide home like PC and are driven by trained volunteers. Patients in VDH receive medical care from their general practitioner and if necessarily, they receive nursing care from a district-nurse.

In the Netherlands, patients with a life expectancy of less than three months have access to a hospice. Nonetheless, the essentials of hospice-care, MDC provided by a multi-professional team, are adopted in daily hospice-care in the Netherlands⁷, the integration of these essentials in Dutch hospices differs principally.

Basic values of patients' centeredness were found in all mission and vision statements. However, recent studies presented that hospice-care seems to be provider-driven instead of patient-needs driven.⁹ Appropriate hospice-care (AHC) arises from a close collaboration of care and treatment of the problems, complaints, wishes and needs of patients in the four dimensions of MDC.¹⁰

Appropriate care in relation to hospice-care is operationalized into six key-concepts: individual care-plan, quality of life, support of family-caregivers, care-relationships, shared

decision-making and preferred location of death.¹⁰ The extent to which AHC is given depends on professional-caregivers' attitudes regarding AHC.

Human attitudes have a predictive value on human practices, as long as the topic of interest is specific¹¹, the attitudes are stable over time, and memories concerning the topic of interest are easy to retrieve.¹² Concluding that knowledge about practices is valuable for exploring attitudes.

Since nurses are most closely involved as professional-caregivers in daily patient care, they are an important target group within the hospices. Therefore, their practices and attitudes on AHC are of the utmost importance to ameliorate appropriate care in hospices.

Given the differences in which Dutch hospices have adopted the core characteristics of hospice-care⁷, this study aimed to discover practices and attitudes on AHC. This knowledge provides insight into the similarities and differences of the implementation of key-concepts in Dutch hospices. Consequently, future research can focus on these similarities and differences by designing an intervention set for professionals to improve AHC. In addition, the results from this study directly contribute to raising awareness regarding the meaning and value of AHC and ameliorate the quality of hospice-care in the Netherlands.

The research question was: What are the practices and attitudes on AHC of nurses working in Dutch hospices?

Methods

Design

An explanatory mixed method study with a quantitative-qualitative sequential design has been performed from January 23, 2017 to June 30, 2017. First, a quantitative phase aimed to determine the practices regarding AHC. Practices are operationalized as the prevalence of specific proceedings during working hours. A survey is conducted to determine these practices.¹³ Afterwards, the qualitative phase was completed to explore the nurses' attitudes by means of focus-groups.

A sequential design was chosen to use the quantitative data for drafting additional topics for the focus-groups and use to the qualitative data to explain the outcomes of the quantitative data. Data of both studies were of equal importance. The integration of both quantitative and qualitative outcomes took place during data-analysis after conducting the qualitative phase of the study (figure 1). As report guideline, the MIXED framework was used.¹⁴

[Figure 1]

Population and domain

The 42 hospices affiliated by the Dutch Association of Hospice-care (DAHC) and the 70 hospices affiliated by the Volunteers Palliative Terminal Care (VPTC) were approached for

recruiting participants. The study population consisted of registered nurses in the Netherlands, who are skilled in spoken and written Dutch language and who are working in a PDH or VDH, or as a district-nurse working in a VDH for at least once a week.

Sample

A convenience sample was applied by inviting all nurses within the DAHC and VPTC hospices to fill in the survey. For the calculation of the sample size, an estimated normal distribution, an estimated population of five nurses per each of the 153 Dutch hospices and a confidence level of 95% has been used. Based on this calculation, the aim was to collect a minimum of 256 returned surveys, 128 from nurses working in PDH and 128 from nurses working in VDH, based on a quota sample.

Participants within the quantitative phase of the study that indicated to have the will to participate in a focus-group, have all been invited for the nearest focus-group. Because the invitation of this nurses did not lead to at least four participants in each focus-group, nurses who did not participate in the survey were also invited to participate. Within the invitation, a proportional spread of nurses working in PDH and VDH has been attempted by purposive sampling.

Data collection

Quantitative data, including participant characteristics, were obtained through an online survey to determine practices regarding the six key-concepts.¹⁰ These six key-concepts were divided into 14 subtopics by the researcher, which were considered as topics for the survey (figure 2).

[Figure 2]

Four focus-groups were performed within the qualitative phase of the study. Three or four focus-groups are standard for one research project to reach data saturation¹⁵, when a minimum number of four to five participants participate in each focus-group.¹⁶

Data analysis

Outcomes of the survey were analysed using descriptive statistics using SPSS 24. Frequencies of the Likert scale items were calculated to discover patterns in the practices of the participants. When missing data occurred, available case analysis is applied within the analysis of the quantitative data. This method involved including all cases with observed values on the variables included in the analysis.¹⁷

Qualitative data were analysed following the conventional content analysis procedure to identify prominent themes and patterns regarding attitudes towards AHC.¹⁸ An inductive approach was chosen, because little is known about practices and attitudes regarding AHC.^{19,20} Encoding of the data was performed using NVIVO 11. The audiotaped focus-groups were transcribed verbatim. The researcher read this transcribed data repeatedly to achieve immersion and obtain a sense of the whole. The inductive approach followed the

steps summarized in table 1.¹⁹ During the analysis process, peer reviewing on each step within the inductive approach was conducted by the principal investigator (EG) as quality enhancement strategy.¹³

For both phases of the study, the participant's characteristics were analysed with descriptive analysing methods. Frequency and mean outcomes of the characteristics were computed to analyse whether the sample of the focus-groups was a reflection of the sample of the survey.

[Table 1]

Study procedures

Topics within the survey consisted of three to sixteen closed-end items. For the closed-end items, a traditional Likert scale was used. The Likert scale items within the survey presumed to be roughly comparable indicators of the underlying construct.¹³ For this reason, the closed-end items were validated by an expert group, consisted of two researchers and one professional from a hospice. Besides the close-end items, six open-end items within the survey, related to the six key-concepts, allowed participants to exemplify the answers on the closed-end items as needed.

A semi-structured topic list was used as guideline for the focus-groups. The topics were based on the six key-concepts and were complemented, based on analysed outcomes within the quantitative phase of the study. Discovered patterns within the outcomes of the closed and open items from the survey that arouse interest in underlying attitudes were added to the topic list of the focus-groups.

Within the quantitative part of the study, nurses were recruited by E-mail, included the informed consent. These emails were sent through the organizations DAHC and VPTC.

Regarding the recruitment for focus-groups, nurses who submitted their willingness to participate in focus-groups within the survey, were recruited by E-mail. When the minimum number of four participants was not reached, hospices in the nearby area were approached by phone and E-mail to recruit nurses within these hospices. Before the start of each focus-group, written consent was obtained from each participant on location.

The focus-group interviews were organized in four PDH in three different provinces in the Netherlands. These settings were chosen based on distribution across the country and reachability to surrounding hospice settings. Characteristics of the participants within the focus-groups were collected on a reply form before the start of each focus-group. The focus-groups were under guidance of a moderator (EG) and an assistant moderator (EB). The moderator led the discussion. After each discussed topic, the moderator provided a short summary to participants about emerging interpretations, and obtained participants' reactions as a member check in an ongoing way, to establish the credibility of the data.¹³ The assistant moderator observed the interaction between participants and took notes about important

expressions of the participants.¹⁵ Each focus-group lasted approximately 90 minutes, therefore time for interchange was not too short without detrimental effect on the concentration curve of the participants.^{15,16}

Ethical issues

The study was conducted according to the principles of the Declaration of Helsinki²¹, and in accordance with the Guideline for Good Clinical Practice.²² According with the Dutch Personal Data Protection Act, data was handled confidentially and anonymously.

Results

Participant characteristics

In total, 312 surveys were completed, 37 were excluded, 275 nurses participated in the survey, 56% PDH. Hospices had 6 beds on average range 2-20.

From the 266/275 participants were women (97%), aged 50 on average. The educational level of 126/275 nurses (46%) was secondary vocational educated, 142/275 (52%) were higher professional educated, 135/275 (49%) had an additional specialization in palliative or hospice-care. Overall, nurses had 25 years' work experience as a nurse, of which 8 years on average in hospice-care.

A total of 19 nurses participated in the focus-groups from 16 hospices, 37% PDH and 8 beds on average. The participants were predominantly women, 84% and the average age was 55. The educational level of 11/19 participants (58%) was secondary vocational educated and 7 (37%) were higher professional educated, 7 nurses had an additional specialization in palliative or hospice-care. Participants had 30 years of work experience as a nurse, of which 9 years on average in a hospice-care. Characteristics are displayed in table 2.

[Table 2]

Individual care-plan

Individual care-plans were always or mostly drafted by 221/243 (91%) nurses, 155/234 (66%) always or mostly used classification systems. Outcomes are displayed in figure 3.

[Figure 3]

Participants indicated a positive attitude regarding the importance of an individual care-plan to provide AHC, as care being tailored to the needs of the individual patient. However, nurses emphatically indicated their needs for preconditions to draft an individual care-plan for each patient. Drafting individual care-plans should fit the daily dynamics within the hospice. The most common obstructing factors were the presence of a classification system which is not aligned to palliative patients, and a shortage of time to draft an individual care-plan. These obstructions led to non-personal standardized care-plans. Attitudes of nurses showed the willingness to invest time in drafting an individual care-plan to deliver

personalized care, but only when time for physical care is not compromised. Finally, nurses who did not work with systematic care-plans in daily practice, indicated the need for education to improve competences.

“We are working from the care-plan and yes, I think that is important. You can put everything in it.”

“The trouble is just that OMAHA is focused on home care, and not necessarily on palliative terminal care in the base. And then you miss things, sometimes.”

Box 1

Quality of life, well-being and comfort

Standardized assessments were always or mostly used by 149/222 nurses (67%).

Guidelines to select appropriate interventions were always or mostly used by 182/212 nurses (86%). However, only 115/237 (49%) nurses used standardized assessments to determine whether a patient had cognitive impairments. Outcomes are displayed in figure 4.

[Figure 4]

Care directed at maintaining quality of life was often associated with the use of measuring tools for patient symptoms. These tools were mostly used to assess multiple symptoms, affecting quality of life, simultaneously. Most nurses also used these tools to discuss the outcoming symptoms with the patient, directly creating an opportunity to speak about difficult subjects. Nevertheless, some participants did not use any tools, assuming they did not overlook symptoms by knowing the content of a tool. They defined measuring tools as unnecessarily (ballast for the patient). In addition, the extent to which the hospice facilitated working with tools, and the multiprofessional teams supported them, determined if nurses are enabled to use tools in daily care. In the end, all nurses' attitudes attach value to aiming the care on optimizing quality of life in end-of-life. The way nurses determine what care therefore is needed differs.

“As a nurse, you go much more focused into the conversation, because you want to get behind specific information and then adjusting the care based on this information.”

“We do not currently have any lists (read as measuring tools) at this time. It's almost not used because we think we do not miss things.”

Box 2

Capacity and burden of family-caregivers

During a patient's stay, 156/219 nurses (71%) always or mostly gained structural insight into capacity and burden of the patient's family-caregivers, interventions were always or mostly based on guidelines by 110/205 nurses (54%). Outcomes are displayed in figure 5.

[Figure 5]

Participants indicated caring for family-caregivers as an essential element of hospice-care. The hospice must be a safe home for family-caregivers. For this reason, participants indicate the importance to gain insight into the capacity and burden, so care can be directed at needs and wishes of family-caregivers. Frequent conversations between nurses and family-caregivers, and the involvement of family-caregivers in the care process of the patient were indicated as most important interventions to establish insight in capacity and burden of family-caregivers. Tools to measure the capacity and burden of family-caregivers were rarely used. When a high burden level was observed, participants indicated to anticipate by stimulating the family-caregiver to take more distance from physical care and save time for being together in the final stage of life. These interventions were rarely based on systematic-based methods.

"You talk about it and you approach them regularly and try to be a safe home for them."

Box 3

The use of existing care-relationships

During admission, 171/201 nurses (85%) always or mostly identified family-caregivers who want to participate in patient care. Also, 179/202 nurses (89%) always or mostly made arrangements with family-caregivers about their role within the patients' care, and 171/198 nurses (86%) always or mostly evaluated these arrangements.

Participants recognized big differences among family-caregivers, regarding their needs to participate in care. Participants indicated care-relationships as important, while patients are pleased to receive care from family-caregivers. In general, two mainstream approaches were identified. First, hospices where the wishes of family-caregivers regarding participation were not explored. Nurses assumed that family-caregivers initially visit the patient to be together in the final stage of life and when family-caregivers would like to participate, they would indicate by themselves. Second, an approach in which participants methodologically map the wishes and needs of the family-caregivers by frequent conversations.

"Some people are there constantly, day and night. Other very specific family-caregivers would rather be just a partner and not help."

“Which care we take over and which care they want to do. That is a very large portion of our admission procedure.”

Box 4

Shared decision-making

Patients were always or mostly involved in care-plan adjustments by 174/199 nurses (87%). Also, 161/199 nurses (81%) always or mostly discussed goals and interventions with patients, enabling them to choose appropriate aims and interventions. Outcomes are displayed in figure 6.

[Figure 6]

Participants related shared decision-making to continuously adjust the care to the needs and wishes of the patient. Apparently big issues like fulfilling last wishes, or continuation of life habits within the hospice were termed as important indicators to achieve shared decision-making. When it comes to insignificant interventions within daily care, participants acknowledged that wishes and needs were less often discussed with patients. During focus-groups, participants became aware that drafting care-plans without involving the patient, and using tools without enabling the patient to self-assess, were missed chances to involve patients in shared decision-making processes.

“Well, I mean, there are a lot of small decisions that may not be very important, but we take it and actually force them to do so.”

Box 5

Preferred location of death

The preferred location of death was always or mostly discussed during admission by 110/207 nurses (53%), 171/205 nurses (83%) evaluated this subject always or mostly during stay. When a patient indicated that the hospice does not meet his or her preferred location of death, 184/205 nurses (90%) always or mostly attempted to change environmental factors, and 188/205 nurses (92%) always or mostly explored possibilities to move the patient to another place to live.

Participants acknowledged the importance of staying and dying at the preferred location of death. However, some participants indicated that when a patient was admitted to a hospice, the hospice is assumed to be the preferred location of death. In contrast, other participants indicated to discuss the preferred location of death with each patient before admission, at admission and during admission. Individual hospice procedures affected the way participants dealt with the discussion of preferred location of death. Patients who were admitted to a hospice based on a wrong indication, or because family-caregivers decided for the patient to move to a hospice, were both indicators for discussing the preferred location of

death with the patient. In the end, nurses' attitudes acknowledge the importance of dying at the preferred location of death, but are not always aware that patients within a hospice are not automatically in the preferred place of death. Hospices that integrate the subject preferred location of death in admitting-procedures, provide more awareness among nurses regarding this subject.

“Perhaps because you often mistakenly assume people come to a hospice and know why they are here and have chosen for it.”

“That sir at room ten, who came and said, “I do not want to be here at all, my family has put me here”.”

Box 6

Discussion

A majority of Dutch nurses indicated that their daily practices were always or mostly in accordance with AHC, regarding the six key-concepts. Only six items constitute an exception, these items were mostly related to the use of standardized methodologies, measuring instruments/score-lists/tools, or guidelines. Furthermore, all key-concepts were acknowledged and nuanced as indicators for AHC. Nurses' competences and the organizational structure within hospices are determinative for nurses' daily practices, even when this is in violation with nurses' attitudes.

According to the six key concepts, other studies, which were non-specific to hospice-care, related similar concepts to appropriate PC. Care directed at maintaining quality of life, well-being and comfort was described by Bolt et al. as care directed at patients wishes²³, Kim et al. as focussing on individual needs and symptom management²⁴, and Edwards described specifically the aiming on spiritual care.²⁵ Support of family-caregivers was described by Bolt et al. and Kim et al.^{23,24} Kim et al. described especially the importance of a “good relationship” between professional-caregivers and family-caregivers.²⁴ Shared decision-making through communication as an indicator for appropriate PC in end-of-life was described by Bolt et al.²³ The discussed preferred location of death was described by Bolt et al. and Wachterman et al.^{23,26}

In addition, three concepts beyond the scope of this research were described. Kim et al. described “being present”, even if the nurse could not do anything, as good patient care.²⁴ Wachterman et al. described PC consultation and do-not-resuscitate orders as quality-enhancing interventions.²⁶

Strengths of the study were the high response rate on the survey and the reached data-saturation in focus-groups. The applied member-check in an ongoing way and the peer reviewed analysed data are strengths of the study. Reliability of the data was increased by

verifying outcomes with participants and among both researchers, reduced the chance on verification bias.

For the quantitative study, two considerations have to be made. First, the unreached quota sample. Second, the presence of missing values within the survey. After the characteristics-related items, 30 nurses dropped-out the survey. Over the entire length of the survey, the number of drop-outs increased to 73 nurses. The dropped-out nurses concerned a random reflection of the total sample (table 3). The increase in missing items increased progressively and does not display any outliers on specific items.

[Table 3]

Two considerations have to be made for the qualitative study. First, the selection process of the participants within the focus-groups. Because too few participants within the survey wanted to participate in focus-groups, nurses who had not participated in the survey were invited. For this reason, a purposive selection of participants, based on equal distribution of characteristics and question-outcomes from the survey, was not possible. Based on characteristics, the qualitative sample demonstrates a reasonable reflection of the quantitative sample, but maximum variation in outcomes of the survey has not been reached within the focus-groups, resulting in selection bias. Second, within the focus-groups, 13/19 participants (68%) worked in a PDH, and from the participating hospices, 10/16 (63%) were PDH. Attitudes of nurses worked in an VDH may be underexposed in this study, also possibly resulting in selection bias.

The outcomes of this study can be used in clinical practice by policymakers within hospices, by fitting the organizational structures within the hospices on the needs of nurses to deliver AHC, and offer appropriate education to the users. The presence of a care-plan tailored to the palliative patient, implementing the use of tools for measuring symptoms of patients and family-caregivers, and enough available time to spent on indirect care tasks are the most important preconditions that nurses experience as necessary to deliver AHC. Nurses working in hospices can use the outcomes of the study by integrating elements of the six key-concepts within daily practice, adapted to the organizational structure within the hospice.

According to the design of this study, implications for future research are discovering the perspectives of professional-caregivers, patients and family-caregivers, regarding AHC. More knowledge is needed about patients and family-caregivers' perspectives to make certain conclusions about the definition and related needs to deliver AHC. As described in done research to appropriate PC, there are possibly more key-concepts that can be related to AHC.

Conclusion

Despite nurses' positive attitudes regarding the key concepts individual care-plan, quality of life, support of family-caregivers, care-relationships, shared decision-making and preferred location of death¹⁰, the key concepts are not fully applied in daily practices of Dutch hospices. Besides nurses' attitudes, nurses' competences and the organizational structure within hospices are the most influencing factors on how AHC is implemented in daily hospice-care. It is characteristic that there seems to be little cooperation and agreement between Dutch hospices in the implementation of innovations. Sometimes procedures and interventions within hospices are scientifically proven, but often interventions are based on existing uses.

To achieve implementation of AHC, more knowledge among nurses and policymakers about ways in which AHC can be implemented and delivered is needed. This results in a strong demand for more research to perspectives of AHC among professional-caregivers, patients and family-caregivers.

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Inductive approach within the qualitative content analysis		
1.	Open coding:	The researcher write notes and headings in the text, while reading it. Then the researcher read through the text again and write as many headings as necessary down in the margins of the text to describe all aspects of the content.
2.	Coding sheets:	The researcher collects the written headings and then place the headings on coding sheets to make a clear overview of the collection of headings.
3.	Grouping:	The researcher groups the written headings on similarity and dissimilarity under higher order headings.
4.	Categorization:	The researcher categorizes the grouped headings. Where the grouping process was focussed on similarity and dissimilarity, the categorization phase aims to describe the phenomenon, to increase understanding and to generate knowledge. In this phase of the induction approach, the researcher comes to decisions through interpretations.
5.	Abstraction:	The researcher formulates a general description of the research topic through generating sub-categories, generic categories and main categories.

Table 1

Participant characteristics	Outcome survey	Outcome focus-groups
Participants	275 (100)	19 (100)
Gender – N (%)		
Female	266 (97)	16 (84)
Missing	3 (1)	
Age in years – N (%)		
20 – 29	13 (5)	
30 – 39	31 (11)	1 (5)
40 – 49	60 (22)	1 (5)
50 – 59	126 (46)	11 (58)
60 – 69	41 (15)	6 (32)
Missing	4 (1)	
Level of education – N (%)		
Secondary vocational educated	126 (46)	11 (58)
Higher professional educated	142 (52)	7 (37)
Scientifically educated	6 (2)	
Missing	1 (0)	1 (5)
Additional specialization in palliative or hospice-care – N (%)		
Yes	135 (49)	7 (37)
No	137 (50)	12 (63)
Missing	3 (1)	
Number of years of working experience as a nurse – N (%)		
1 – 9	38 (14)	1 (5)
10 – 19	46 (17)	2 (11)
20 – 29	64 (23)	5 (26)
30 – 39	69 (25)	7 (37)
40 – 49	39 (14)	4 (21)
Missing	19 (7)	
Number of years of working experience in hospice-care – N (%)		
1 – 9	163 (59)	10 (53)
10 – 19	84 (31)	8 (42)
>19	5 (2)	1 (5)
Missing	23 (8)	
Kind of hospice setting – N (%)		
Professional driven hospice	154 (56)	12 (63)
Voluntary driven hospice	117 (43)	6 (32)
Missing	4 (1)	1 (5)
Number of beds available in hospice setting – N (%)		
1 – 3	13 (5)	
4 – 6	155 (56)	9 (48)
7 – 9	73 (27)	4 (21)
10 – 12	31 (11)	5 (26)
>12	1 (0)	1 (5)
Missing	2 (1)	

Table 2

Characteristics participants dropped-out in survey	Total sample	Drop-out before first item	Drop-out after first item
Participants	275 (100)	30 (100)	43 (100)
Gender – N (%)			
Female	266 (97)	29 (97)	43 (100)
Missing	3 (1)	1 (3)	
Age in years – N (%)			
20 – 29	13 (5)	3 (10)	1 (2)
30 – 39	31 (11)	3 (10)	2 (4)
40 – 49	60 (22)	5 (17)	8 (19)
50 – 59	126 (46)	15 (50)	24 (56)
60 – 69	41 (15)	3 (10)	8 (19)
Missing	4 (1)	1 (3)	
Level of education – N (%)			
Secondary vocational educated	126 (46)	14 (47)	18 (42)
Higher professional educated	142 (52)	15 (50)	23 (53)
Scientifically educated	6 (2)		2 (5)
Missing	1 (0)	1 (3)	
Additional specialization in palliative or hospice-care – N (%)			
Yes	135 (49)	11 (37)	22 (51)
No	137 (50)	18 (60)	21 (49)
Missing	3 (1)	1 (3)	
Number of years of working experience as a nurse – N (%)			
1 – 9	38 (14)	4 (13)	2 (5)
10 – 19	46 (17)	7 (24)	7 (16)
20 – 29	64 (23)	6 (20)	9 (21)
30 – 39	69 (25)	5 (17)	11 (25)
40 – 49	39 (14)	4 (13)	8 (19)
Missing	19 (7)	4 (13)	6 (14)
Number of years of working experience in hospice-care – N (%)			
1 – 9	163 (59)	20 (67)	18 (42)
10 – 19	84 (31)	3 (10)	15 (35)
>19	5 (2)		3 (7)
Missing	23 (8)	7 (23)	7 (16)
Kind of hospice setting – N (%)			
Professional driven hospice	154 (56)	16 (53)	23 (53)
Voluntary driven hospice	117 (43)	12 (40)	18 (42)
Missing	4 (1)	2 (7)	2 (5)
Number of beds available in hospice setting – N (%)			
1 – 3	13 (5)	2 (7)	1 (2)
4 – 6	155 (56)	17 (56)	23 (54)
7 – 9	73 (27)	6 (20)	12 (28)
10 – 12	31 (11)	3 (10)	6 (14)
>12	1 (0)		1 (2)
Missing	2 (1)	2 (7)	

Table 3

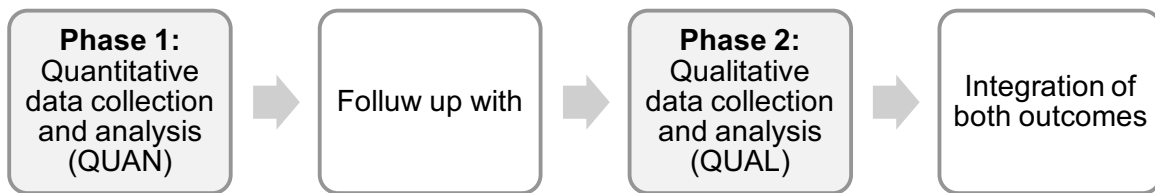


Figure 1

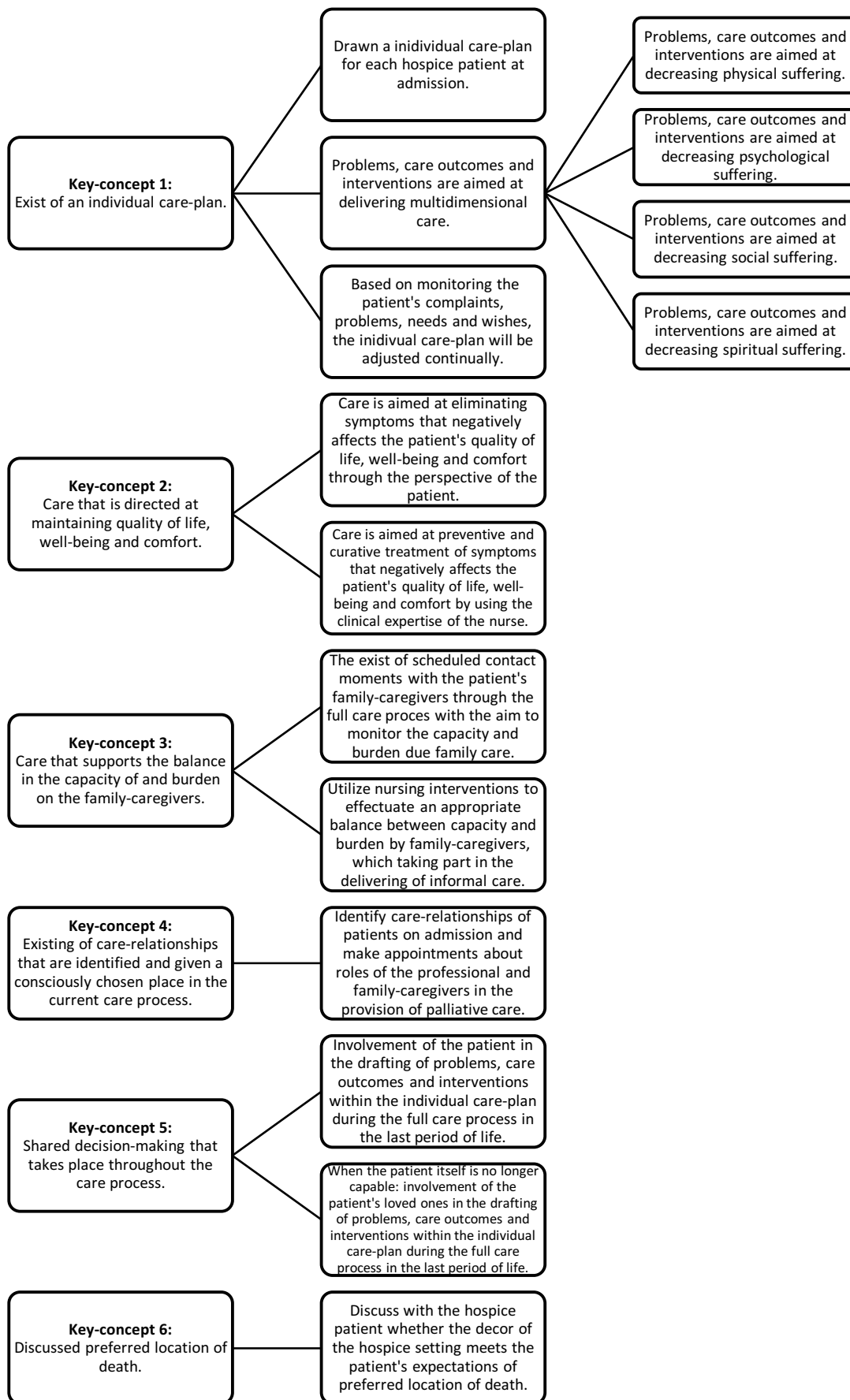


Figure 2

Outcomes survey on key-concept individual care-plan

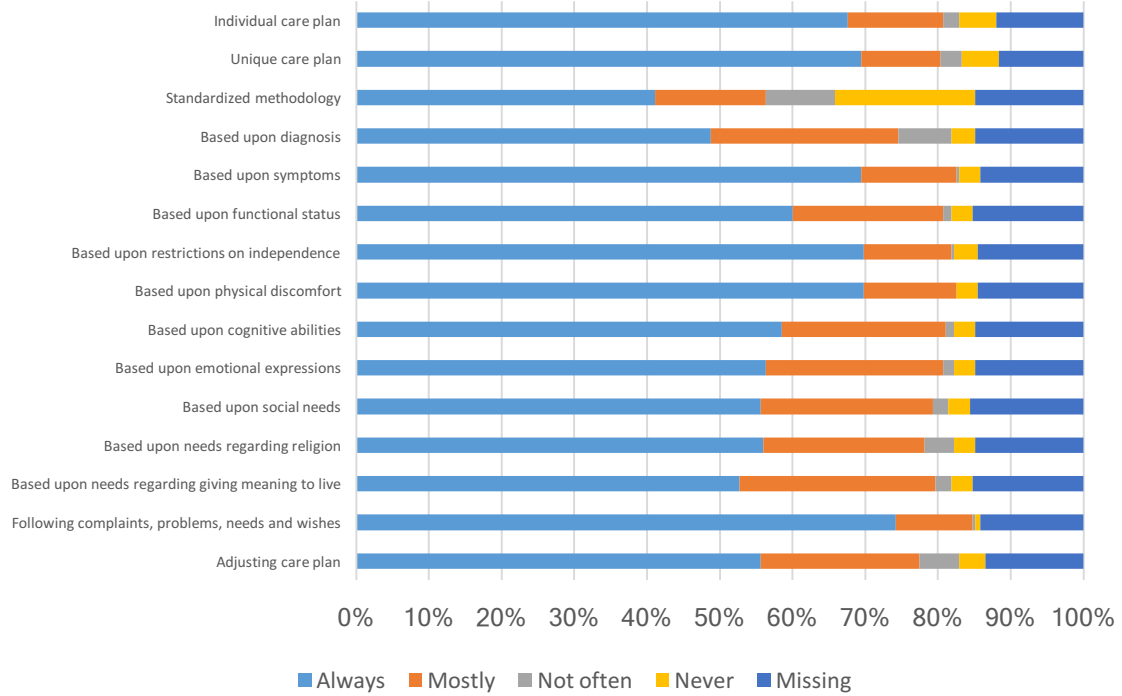


Figure 3

Outcomes survey on key-concept quality of life, well-being and comfort

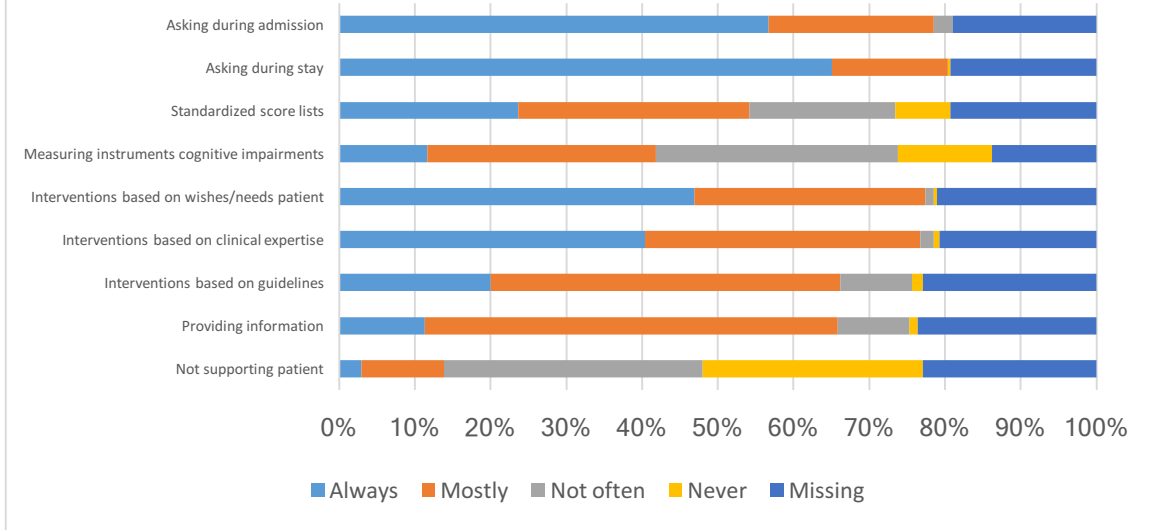


Figure 4

Outcomes survey on key-concept capacity and burden of family-caregivers

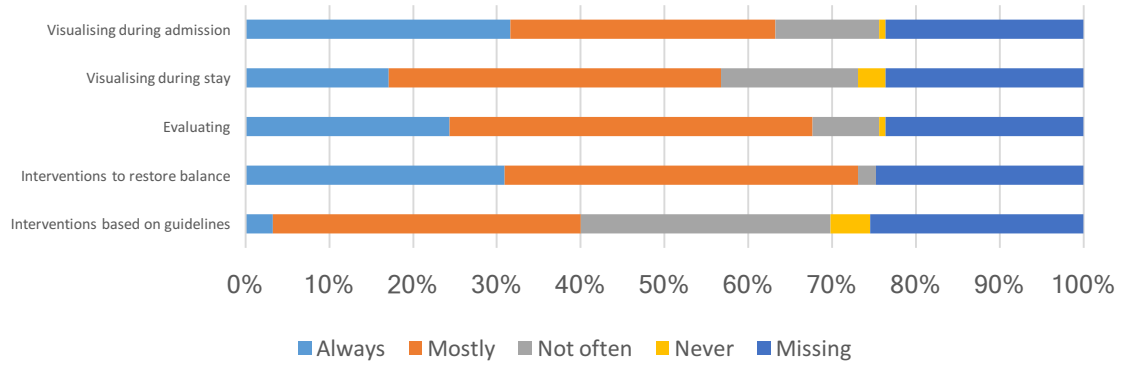


Figure 5

Outcomes survey on key-concept shared decision-making

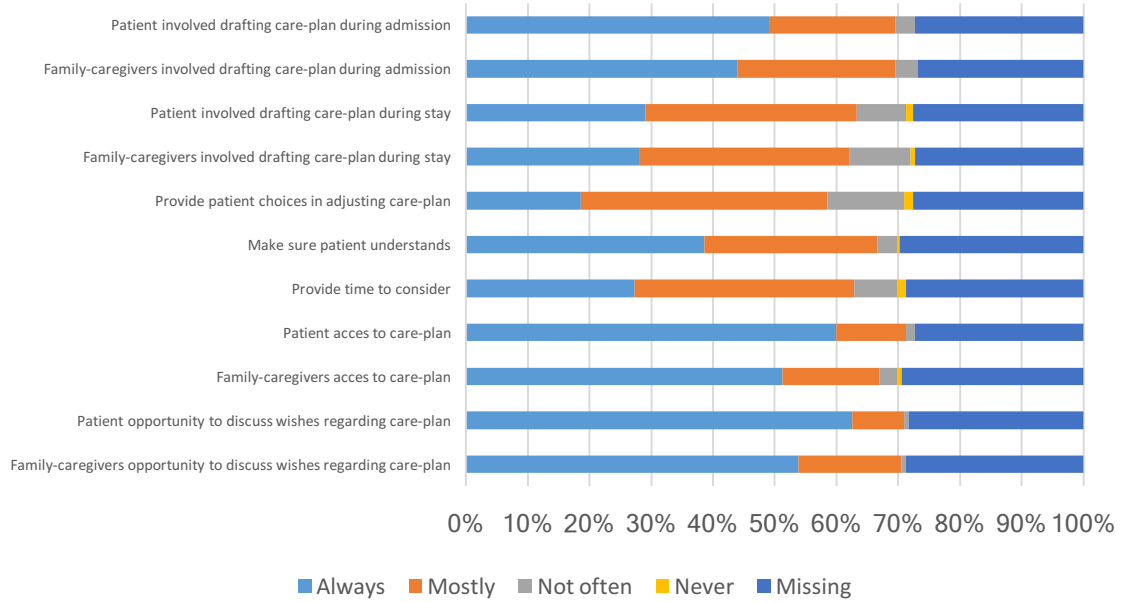


Figure 6

Appendix 1: Survey (Dutch)

1. Inclusievragen			
a)	Bent u onder vaste aanstelling werkzaam als verpleegkundige in een hospice of bijna thuis huis?	<input type="checkbox"/> Ja ¹	<input type="checkbox"/> Nee ²
b)	Bent u onder vaste aanstelling werkzaam als coördinator in een bijna thuis huis?	<input type="checkbox"/> Ja ³	<input type="checkbox"/> Nee ⁴
c)	Bent u als wijkverpleegkundige gemiddeld eenmaal per week werkzaam als verpleegkundige in een hospice/bijna thuis huis?	<input type="checkbox"/> Ja ⁵	<input type="checkbox"/> Nee ⁶

^{1,3,5}Participant wordt doorgestuurd naar vraag 2a.

²Participant wordt doorgestuurd naar vraag 1b.

⁴Participant wordt doorgestuurd naar vraag 1c.

⁶Participant voldoet niet aan inclusiecriteria en wordt bedankt voor deelname.

2. Persoonsgebonden (beroeps)eigenschappen			
a)	Wat is uw geslacht?	<input type="checkbox"/> Vrouw	<input type="checkbox"/> Man
b)	Wat is uw leeftijd in jaren?		
c)	Wat is uw opleidingsniveau?	<input type="checkbox"/> MBO	<input type="checkbox"/> HBO
			<input type="checkbox"/> WO
d)	Heeft u een aanvullende specialisatie in palliatieve en/of hospicezorg afgerond?	<input type="checkbox"/> Ja	<input type="checkbox"/> Nee
e)	Hoeveel jaren werkervaring heeft u als verpleegkundige (naar boven afgerond in hele jaren)?		
f)	In wat voor hospice bent u werkzaam?	<input type="checkbox"/> High care hospice	<input type="checkbox"/> Bijna thuis huis
g)	Wat is de naam van het hospice waar u werkzaam bent?		
h)	Hoeveel bedden zijn er beschikbaar binnen uw hospice?		
i)	Hoeveel jaren werkervaring heeft u als verpleegkundige in een hospice (naar boven afgerond in hele jaren)?		

3. Individueel multidimensioneel zorgplan		ALTIJD	MEESTAL	VAAK NIET	NOOIT
a)	Stelt u voor uw patiënt een zorgplan op bij opname?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	Maakt u een persoonlijk zorgplan, dat voor iedere patiënt uniek is?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	Verwerkt u in het zorgplan problemen, doelen en interventies volgens een gestandaardiseerde methodiek, zoals ISF, OMAHA of NANDA, NOC & NIC?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	Stemt u in uw zorgplan de opgestelde problemen, doelen en interventies af op de diagnoses van de patiënt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e)	Stemt u in uw zorgplan de opgestelde problemen, doelen en interventies af op de symptomen van de patiënt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f)	Stemt u in uw zorgplan de opgestelde problemen, doelen en interventies af op de functionele status van de patiënt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

g)	Stemt u in uw zorgplan de opgestelde problemen, doelen en interventies af op de patiënt zijn of haar beperkingen ten aanzien van ADL-zelfstandigheid?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h)	Stemt u in uw zorgplan de opgestelde problemen, doelen en interventies af op klachten of problemen die volgens de patiënt leiden tot lichamelijk ongemak?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i)	Stemt u in uw zorgplan de opgestelde problemen, doelen en interventies af op de cognitieve vermogens van de patiënt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j)	Stemt u in uw zorgplan de opgestelde problemen, doelen en interventies af op de emotionele uitingen van de patiënt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k)	Stemt u in uw zorgplan de opgestelde problemen, doelen en interventies af op de sociale behoeften van de patiënt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l)	Stemt u in uw zorgplan de opgestelde problemen, doelen en interventies af op de behoeften en rituelen van de patiënt, voortkomend uit een geloofsovertuiging?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m)	Stemt u in uw zorgplan de opgestelde problemen, doelen en interventies af op de behoeften van de patiënt met betrekking tot zingeving (denk hierbij aan het kunnen uitvoeren van activiteiten waar de patiënt belang aan hecht in relatie tot het zichzelf plezierig en/of waardevol voelen)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n)	Volgt u gedurende het verblijf van uw patiënt zijn of haar klachten, problemen, behoeften en wensen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o)	Stelt u gedurende het verblijf van uw patiënt het zorgplan bij op grond van wijzigingen in de toestand van de patiënt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p)	Wanneer u behoefte heeft om één of meerdere van uw antwoorden op bovenstaande vragen toe te lichten, kunt u dat hier doen:				

4.	Zorg gericht op behoud van kwaliteit van leven, welzijn en comfort	ALTIJD	MEESTAL	VAAK NIET	NOOIT
a)	Vraagt u tijdens de opname van uw patiënt gericht naar klachten die de kwaliteit van leven van de patiënt nadelig beïnvloeden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	Volgt u tijdens het verblijf van uw patiënt de aanwezige klachten die de kwaliteit van leven van de patiënt nadelig beïnvloeden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	Maakt u gebruik van gestandaardiseerde scorelijsten om klachten van uw patiënt te volgen die de kwaliteit van leven van de patiënt nadelig beïnvloeden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	Maakt u gebruik van meetinstrumenten om cognitieve beperkingen bij een patiënt vast te stellen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e)	Zet u op grond van de wensen en behoeften van uw patiënt interventies in om symptomen, die de ervaren kwaliteit van leven nadelig beïnvloeden, in ernst te doen reduceren?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f)	Zet u op grond van uw klinische expertise interventies in bij uw patiënt om symptomen in ernst te doen reduceren, wanneer deze symptomen de kwaliteit van leven van de patiënt nadelig beïnvloeden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g)	Maakt u gebruik van richtlijnen voor het selecteren van geschikte interventies met als doel symptomen reduceren of wegnemen die de kwaliteit van leven nadelig beïnvloeden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

h)	Wanneer u op grond van klinische expertise observeert dat de wensen en behoeften van uw patiënt nadelig van invloed kunnen zijn op zijn of haar ervaren kwaliteit van leven, probeert u de patiënt dan op grond van informatieverstrekking op andere gedachten te brengen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i)	Wanneer u op grond van klinische expertise observeert dat de wensen en behoeften van uw patiënt nadelig van invloed kunnen zijn op zijn of haar ervaren kwaliteit van leven, zou u de patiënt dan bewust niet ondersteunen in de tegemoetkoming aan deze wensen en behoeften?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j)	Wanneer u behoefte heeft om één of meerdere van uw antwoorden op bovenstaande vragen toe te lichten, kunt u dat hier doen:				

5. Naastenondersteuning		ALTIJD	MEESTAL	VAAK NIET	NOOIT
a)	Is het in kaart brengen van de draagkracht en draaglast van betrokken naasten een standaard onderdeel van het opnamegesprek van nieuwe patiënten in uw hospice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	Maakt u gedurende het verblijf van uw patiënt de draagkracht en draaglast van de naasten structureel herhaaldelijk inzichtelijk?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	Evalueert u gedurende het verblijf van uw patiënt de draagkracht en draaglast van de naasten?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	Wanneer u tijdens het verblijf van uw patiënt signaleert dat de draaglast groter is dan draagkracht van een naaste van de patiënt, zet u dan interventies in om deze naaste te ondersteunen bij het (voor zover als mogelijk) herstellen van het evenwicht tussen draagkracht en draaglast?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e)	Wanneer u interventies inzet met als doel het herstellen van het evenwicht tussen draagkracht en draaglast onder naasten van uw patiënt, selecteert u deze interventies dan op grond van actuele richtlijnen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f)	Wanneer u behoefte heeft om één of meerdere van uw antwoorden op bovenstaande vragen toe te lichten, kunt u dat hier doen:				

6. Afspraken omtrent mantelzorgaanbod		ALTIJD	MEESTAL	VAAK NIET	NOOIT
a)	Identificeert u bij opname van uw patiënt of hij of zij mantelzorgers in de naaste omgeving heeft die willen en kunnen participeren in de zorg?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	Maakt u tijdens opname van uw patiënt afspraken met de patiënt en zijn of haar mantelzorgers over de rollen die mantelzorgers willen en kunnen betekenen binnen de zorg?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	Evalueert u tijdens het verblijf van uw patiënt het mantelzorgaanbod en maakt u nieuwe afspraken omtrent het mantelzorgaanbod wanneer hier behoefte aan, of noodzaak toe is?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	Wanneer u behoefte heeft om één of meerdere van uw antwoorden op bovenstaande vragen toe te lichten, kunt u dat hier doen:				

7. Gedeelde besluitvorming		ALTIJD	MEESTAL	VAAK NIET	NOOIT
a)	Heeft uw patiënt rondom opname inspraak in het opgestelde zorgplan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	Hebben naasten van uw patiënt rondom opname inspraak in het opgestelde zorgplan, wanneer de patiënt hier zelf niet toe in staat is?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	Betrekt u uw patiënt gedurende het verblijf in het bijstellen van het zorgplan op grond van wijzigingen in de toestand van de patiënt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	Betrekt u naasten van uw patiënt gedurende het verblijf in het bijstellen van het zorgplan op grond van wijzigingen in de toestand van de patiënt, wanneer de patiënt hier niet toe in staat is?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e)	Wordt uw patiënt ten tijde van bijstelling van het zorgplan keuzes aangereikt met betrekking tot het stellen van doelen en interventies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f)	Wanneer u met een patiënt en/of naasten afspraken maakt omtrent de inhoud van het zorgplan, gaat u dan bewust na of de patiënt/naasten inhoudelijk hebben begrepen wat u aan hen heeft uitgelegd.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g)	Wanneer u met een patiënt en/of naasten afspraken maakt omtrent de inhoud van het zorgplan, biedt u de patiënt en/of naasten dan bedenktijd aan wanneer wenselijk.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h)	Heeft uw patiënt op ieder moment mogelijkheid tot inzage in zijn of haar eigen zorgdossier en zorgplan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i)	Hebben naasten van uw patiënt op ieder moment inzage in het zorgdossier en zorgplan van de patiënt, wanneer de patiënt hier niet toe in staat is en inzagerecht heeft gegeven?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j)	Heeft uw patiënt de mogelijkheid om op ieder moment in het zorgproces zijn of haar wensen ten aanzien van bijstelling van het zorgplan bespreekbaar te maken?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k)	Hebben naasten van uw patiënt de mogelijkheid om op ieder moment in het zorgproces hun wensen ten aanzien van bijstelling van het zorgplan bespreekbaar te maken, wanneer de patiënt hier niet toe in staat is?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l)	Wanneer u behoefte heeft om één of meerdere van uw antwoorden op bovenstaande vragen toe te lichten, kunt u dat hier doen:				

8. Voorkeurslocatie van overlijden		ALTIJD	MEESTAL	VAAK NIET	NOOIT
a)	Maakt u bij opname van uw patiënt de voorkeurslocatie van overlijden bespreekbaar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	Wanneer uw patiënt kenbaar maakt dat het hospice niet voldoet aan zijn of haar voorkeurslocatie van overlijden, probeert u dan factoren in de omgeving van de patiënt aan te passen waardoor het hospice meer aan deze behoeften tegemoetkomt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	Wanneer uw patiënt kenbaar maakt dat het hospice niet voldoet aan zijn of haar voorkeurslocatie van overlijden, verkent u dan mogelijkheden om de patiënt te begeleiden naar een andere woonomgeving die wel voldoet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

d)	Evalueert u gedurende het verblijf van uw patiënt herhaaldelijk of de hospice-omgeving tegemoetkomt aan de behoeften en wensen van de patiënt ten aanzien van de plaats van overlijden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e)	Wanneer u behoefte heeft om één of meerdere van uw antwoorden op bovenstaande vragen toe te lichten, kunt u dat hier doen:				

9.	Vervolgonderzoek	JA	NEE
	Dit onderzoek krijgt een vervolg in de vorm van een onderzoek waarin zogenaamde focusgroep-interviews (groepsinterviews) centraal staan. Bent u bereid benaderd te worden voor deelname aan dit onderzoek?	<input type="checkbox"/> Vul hier uw E-mailadres in:	<input type="checkbox"/>

Appendix 2: Survey-questions (translated to English)

Question 1	<i>Do you draft a care-plan for your patient at admission?</i>
Question 2	<i>Do you draft a care-plan that is unique to each patient?</i>
Question 3	<i>Do you address problems, goals and interventions in the care-plan according to a standardized methodology, such as ISF, OMAHA or NANDA, NOC & NIC?</i>
Question 4	<i>Are problems, goals and interventions within the care-plan based upon the patient's diagnosis?</i>
Question 5	<i>Are problems, goals and interventions within the care-plan based upon the patient's symptoms?</i>
Question 6	<i>Are problems, goals and interventions within the care-plan based upon the patient's functional status?</i>
Question 7	<i>Are problems, goals and interventions within the care-plan based upon the patient's restrictions on independence, regarding general daily life?</i>
Question 8	<i>Are problems, goals and interventions within the care-plan based upon complaints or problems which, according to the patient, lead to physical discomfort?</i>
Question 9	<i>Are problems, goals and interventions within the care-plan based upon cognitive abilities of the patient?</i>
Question 10	<i>Are problems, goals and interventions within the care-plan based upon emotional expressions of the patient?</i>
Question 11	<i>Are problems, goals and interventions within the care-plan based upon social needs of the patient?</i>
Question 12	<i>Are problems, goals and interventions within the care-plan based upon needs and rituals of the patient, arising from religion?</i>
Question 13	<i>Are problems, goals and interventions within the care-plan based upon patient's needs regarding giving meaning to life?</i>
Question 14	<i>Do you follow your patient's complaints, problems, needs and wishes during the patient's stay in the hospice?</i>
Question 15	<i>During the stay of your patient, do you adjust the care-plan based on changes in the patient's condition?</i>
Question 16	<i>During admission, are you asking for patient's complaints that adversely affect the quality of life?</i>
Question 17	<i>During stay, do you follow the patient's complaints which adversely affect the quality of life?</i>
Question 18	<i>Do you use standardized score-lists to follow patient's complaints that adversely affect the quality of life?</i>
Question 19	<i>Do you use measuring instruments to determine cognitive impairments in a patient?</i>
Question 20	<i>Based on the wishes and needs of your patient, do you put in interventions to reduce symptoms that adversely affect the quality of life?</i>
Question 21	<i>Based on your clinical expertise, do you put in interventions to reduce symptoms in severity when these symptoms adversely affect the quality of life of the patient?</i>
Question 22	<i>Do you use guidelines for selecting appropriate interventions to reduce or eliminate symptoms that adversely affect the quality of life?</i>
Question 23	<i>If, based on clinical expertise, you observe that your patient's wishes and needs may adversely affect his or her experienced quality of life, do you try to bring the patient to other thoughts based on providing information?</i>
Question 24	<i>If, based on clinical expertise, you observe that your patient's wishes and needs may adversely affect his or her experienced quality of life, would you consciously not support the patient in meeting these wishes and needs?</i>
Question 25	<i>Is visualising the capacity and burden of family-caregivers a standard procedure within the admission of new patients in your hospice?</i>
Question 26	<i>During the stay of your patient, do you make the capacity and burden of family-caregivers structurally insightful?</i>
Question 27	<i>During the stay of your patient, do you evaluate the capacity and burden of family-caregivers?</i>
Question 28	<i>During the stay of your patient, when you notice that the family-caregivers' burden is greater than the family-caregivers' capacity, do you put in interventions to support this family-caregivers in restoring the balance between burden and capacity as far as possible?</i>
Question 29	<i>When you use interventions with the aim of restoring the balance between family-caregivers' capacity and burden, do you select these interventions according to current guidelines?</i>
Question 30	<i>At admission, do you identify patients' care-relationships in the immediate vicinity who wants to participate in daily care?</i>
Question 31	<i>At admission, do you make appointments with the patient and his or her family caretakers about the roles that the family caretakers can fulfil within the care process?</i>
Question 32	<i>During the stay of your patient, do you evaluate the care provided by family caretakers and do you make new arrangements regarding the care provided by family caretakers when needed or necessary?</i>
Question 33	<i>During admission, is your patient involved in drafting the care-plan?</i>
Question 34	<i>During admission, are family-caregivers of your patient involved in drafting the care-plan, when the patient is unable to do so?</i>
Question 35	<i>During the stay of your patient, do you involve your patient in adjusting the care-plan based on changes in the patient's condition?</i>
Question 36	<i>During the stay of your patient, do you involve family-caregivers of your patient in adjusting the care-plan based on changes in the patient's condition, when the patient is unable to do so?</i>
Question 37	<i>Will your patient be provided in making choices regarding the setting of goals and interventions at</i>

	<i>time of adjusting the care-plan?</i>
Question 38	<i>When you agree with a patient and/or his/her family-caregivers about the content of the care-plan, do you make sure that they understand what you have explained to them.</i>
Question 39	<i>When you agree with a patient and/or his/her family-caregivers about the content of the care-plan, do you provide them time to consider when desirable?</i>
Question 40	<i>Does your patient have access to his or her own care file and care-plan at any time?</i>
Question 41	<i>Does your patient's family-caregivers have access to the patient's care file and care-plan at any time, when the patient is unable to do so?</i>
Question 42	<i>Does your patient have the opportunity to discuss his or her wishes regarding the adjustment of the care-plan at any time in the care process?</i>
Question 43	<i>Does your patient's family-caregivers have the ability to discuss their wishes regarding adjustment of the care-plan at any time in the care process when the patient is unable to do so?</i>
Question 44	<i>At admission, do you discuss the preferred location of death of your patient?</i>
Question 45	<i>When your patient indicates that the hospice does not meet his or her preferred location of death, do you try to adjust environmental factors which makes the hospice more suited to these needs?</i>
Question 46	<i>When your patient indicates that the hospice does not meet his or her preferred location of death, do you explore possibilities to guide the patient to another living environment that suits this preferred location of death?</i>
Question 47	<i>During the stay of your patient, do you repeatedly evaluate whether the hospice environment meets the patient's needs and wishes regarding the preferred location of death?</i>