

Evaluating the PalliSupport care pathway to improve palliative care and quality of life

Name: D.L. Burggraaff
Student number: 6212816
Course: Afstudeeronderzoek/Research internship 2: Master Thesis

Status: Definitive
Date: 18-6-2020
Number of words: 3786
Number of words abstract: 300
Number of words Dutch abstract: 299
Reference style: Vancouver

Name lecturer: J.M. de Man (MSc, PhD, RN)

Master Clinical Health Sciences (KGW) Nursing Science, Utrecht University.

Name supervisors: Marije Holstege (MSc, PhD) en Marjon van Rijn (RN, PhD)
Internship institution: AMC Amsterdam Universitaire Medische Centrum
(Amsterdam UMC, locatie AMC)

Intended journal: Journal of Nursing studies
Reporting guidelines: MOREcare

Abstract

Background: Patients, families and healthcare professionals have experienced barriers in palliative care. To support patients and reduce these barriers, the PalliSupport care pathway was developed. However, since this care pathway was implemented for the first time, the experiences and perspectives of patients as well as the process of implementation are still unknown. It is important to understand how the PalliSupport care pathway influences outcomes and to gain insight into its implementation before carrying out the care pathway.

Aim: To explore the experiences and perspectives of patients in the palliative phase of the PalliSupport care pathway and to provide insight into what extent the components, according to study protocol, of the PalliSupport care pathway were implemented.

Methods: A convergent parallel mixed-method design was conducted. Qualitative and quantitative data were collected through semi-structured interviews, questionnaires, study records and electronic health records.

Results: After conducting interviews with patients, it was discovered they had different expectations of the conversations and their hospital care or they had not thought about end-of-life. Furthermore, expectations of PalliSupport changed in the hospital and at home. Some patients thought the hospital was the right place to talk about palliative care, while other patients did not remember the conversations.

In total, 29 components of the PalliSupport care pathway were implemented and measured. The extent of implementation for these components ranged from 0.0% to 94.4%. In the lowest component, no district nurse was invited for a warm handover in the hospital. In the highest component, the general practitioners received a medical handover.

Conclusion: A first overview is given of the experiences and perspectives of patients and the implemented components of the PalliSupport care pathway. It is important to accommodate the wishes of patients and to conduct in-depth research into some components.

Keywords: Palliative care, end-of-life care, process evaluation, interdisciplinary, mixed-methods.

Nederlandse samenvatting

Achtergrond: Patiënten, familieleden en zorgprofessionals ervaren barrières in palliatieve zorg. Om deze barrières te verminderen is het PalliSupport zorgpad ontwikkeld. De ervaringen en perspectieven van patiënten met het zorgpad zijn nog onbekend en het proces van implementatie is nog niet onderzocht, omdat dit de eerste implementatie is van het zorgpad. Het is belangrijk om te onderzoeken wat voor invloed het zorgpad heeft op uitkomsten om inzicht te creëren in het proces van implementatie voor het implementeren van het zorgpad.

Doel: Het verkennen van de ervaringen en perspectieven van het PalliSupport zorgpad van patiënten in de palliatieve fase. Hiernaast inzicht creëren in hoeverre de componenten, volgens het studieprotocol, van het PalliSupport zorgpad zijn geïmplementeerd.

Methode: Een convergente parallel mixed methode is uitgevoerd, waarbij kwalitatieve en kwantitatieve data is verzameld. Dit is gedaan door middel van vragenlijsten, studie records, patiëntendossier en semigestructureerde interviews.

Resultaten: De patiënten hadden andere verwachtingen van de gesprekken, de ontvangen ziekenhuiszorg of waren niet bezig met de dood. Daarnaast veranderde de verwachtingen in het ziekenhuis en thuis. Sommige patiënten vonden het ziekenhuis de juiste plek om over palliatieve zorg te praten en waren tevreden over de ontvangen zorg. Echter waren er sommige patiënten die de gesprekken in het ziekenhuis en thuis niet konden herinneren. In totaal zijn er 29 componenten geïmplementeerd en geëvalueerd. De geïmplementeerde componenten lagen tussen de 0.0% en 94.4%. Het laagste component was dat de wijkverpleegkundige werd uitgenodigd voor een warme overdracht. Het hoogste component was het aantal overdrachten naar de huisarts.

Conclusie: Deze studie geeft inzicht in de eerste ervaringen en perspectieven van patiënten en van de geïmplementeerde componenten van het zorgpad. Het is belangrijk dat het zorgpad aansluit op de wensen van patiënten. Daarnaast hebben sommige componenten nog verdiepend onderzoek nodig.

Sleutelwoorden: Palliatieve zorg, zorg laatste levensfase, procesevaluatie, interdisciplinair, mixed-methode.

1. Introduction

In 2019, 19.2% of the population in the Netherlands was 65 years or older, hereafter called the elderly. That year, 3.4% of the elderly died.¹ The leading causes of death were dementia, lung cancer, stroke and vascular heart diseases.² Patients that suffer from a terminal disease are eligible for palliative care.³ Palliative care focuses on symptom treatment, enhancing quality of life, providing care according to the wishes of patients as well as supporting patients that have life-threatening conditions and their informal caregivers.⁴ Although it is unclear how many of the deceased in 2019 received palliative care, it is expected that the need for palliative care will increase over time as the population ages and as (multi-) chronic diseases rise.⁵

There are many barriers for elderly patients, their family and healthcare professionals regarding palliative care.⁶⁻⁹ Incorrect admissions, not recognizing the needs of patients and inadequate communication from healthcare professionals have caused burdens for patients and their informal caregivers.^{10,11,20-22,12-19} As a result, according to healthcare professionals, palliative care patients are often unnecessarily, and through no accordance to patients' wishes, admitted to general practices or first aid.^{23,24}

To reduce these barriers, the PalliSupport care pathway (PSCP) was developed.²⁵ The PSCP is a transitional care pathway focusing on improving the quality of care for elderly patients as they near the end of their lives. The PSCP guides healthcare professionals to support their patients from diagnosis until end-of-life and starts when palliative patients are admitted to the hospital and continues when the patients go home.^{25,26}

The PSCP has been developed in line with the palliative care quality framework in the Netherlands using the Medical Research Council (MRC) evaluation framework to develop the intervention.^{27,28} The MRC framework consists of four phases to support the development of complex interventions: development, feasibility and piloting, evaluation and implementation.^{27,29} Although the PSCP has been implemented, it is still important to conduct the evaluation phase to understand how the PSCP influences outcomes and to provide insight in the process of implementation before fully implementing the PSCP in order to explore unanticipated outcomes or reasons for a successful intervention.^{28,30} The evaluation phase exists of a process evaluation and an effect evaluation.^{30,31} This study will focus on the process evaluation with an emphasis on assessing the quality of implementation and the experiences and perspectives of patients.^{27,29} The goal is to see if the patients felt supported, more informed, received care according to their wishes and had a reduced burden.

Furthermore, the study will also strive to gain information on how the PSCP was delivered. Therefore, the aim of this study is to explore the experiences and perspectives of patients in the palliative phase of the PalliSupport care pathway and to provide insight into what extent the components, according to study protocol, of the PalliSupport care pathway were

implemented.

2. Methods

2.1. Study Design

A convergent parallel mixed-method design was conducted to provide insight into what extent the components, according to study protocol, were implemented as intended and to explore the experiences and perspectives of patients in the use of the PSCP.^{32,33} This study is part of the process evaluation of the main study: PalliSupport a transitional care pathway for elderly patients at the end-of-life.^{25,26}

A mixed-method design was conducted to focus on analysing qualitative and quantitative data to enable different perspectives within the process evaluation.^{32,33} A mixed-method design exists of different approaches. To compare and confirm the qualitative and quantitative data, a convergent parallel approach was conducted. Within this approach, the qualitative and quantitative data were collected and analyzed simultaneously in parallel of each other.^{32,33}

Within the process evaluation, this study focused on two components of the process evaluation, dose delivered and dose received.^{28,34} Dose delivered measured how many components of the PSCP were delivered according to study protocol.³⁰⁻³² The components of the PSCP are presented in Table 1. Dose received was separated by satisfaction and exposure. Satisfaction measured the patients' experiences and perspectives with the PSCP. Exposure measured if the patients understood the information from the PSCP.

-Table 1 approximately here-

2.2. Population and Domain

The main study's population consists of patients of ≥ 65 years old who were acutely admitted for >48 hours to the departments of internal medicine, geriatrics, cardiology, pulmonary disease, gastroenterology or oncology.^{25,26} The patients had a positive result on the Surprise Question (SQ) screening tool to identify patients in the palliative phase.³⁵ Furthermore, patients had a positive criteria on the Supportive and Palliative Indicators tool (SPICTTM).^{35,36} The SPICTTM criteria are a set of general and clinical indicators that determine the need for palliative care. Moreover, the patients had the ability to read and speak the Dutch language.^{25,26} Patients who were not able to answer questionnaires due to severe cognitive impairment after a diagnosis of dementia or active delirium during the entire admission were excluded from the main study. Patients who lived far from the hospital and therefore were not able to be visited by the palliative care team were also excluded.^{25,26}

The study population of this study exists out of the population of the main study and were recruited through convenience sampling.^{25,26} However, this study will only focus on the patients admitted to a non-academic hospital located in the Gooi and Vechtstreek region in the Netherlands.³⁷

2.3. Data Collection

The qualitative and quantitative data were collected parallel to each other. The qualitative data was collected for the components of dose received: satisfaction and dose received: exposure. The quantitative data was collected for the components of dose delivered and dose received: exposure. See Figure 1 for an overview of data collection and Table 2 for an overview of each component.

- Figure 1 and table 2 approximately here -

2.4.1. Qualitative Data

The qualitative data was collected through semi-structured interviews. Data was collected between February 23, 2020, and February 28, 2020. The interviews were conducted at the participants home and an interview guide was used. The interview guide was developed based on literature about palliative care and a framework for complexity in palliative care with the goal of incorporating all important subjects.^{3,38-41} Each interview was audio recorded and field notes were taken after each interview.

2.4.2. Quantitative Data

The quantitative data was collected through questionnaires, study records and electronic health records (EHR). Data was collected between October 2019 and April 2020. The patients were asked to answer questionnaires at baseline as well as at the two-, four-, twelve- and 24-week periods after discharge. The collected information from the questionnaires, study records and EHR focused on the sociodemographic characteristics and indicators that indicate the development of the process of the PSCP implementation. The sociodemographic characteristics and process indicators are shown in Tables 3 and 5.

2.5. Data Analysis

The qualitative and quantitative data were analyzed according to the components of the mixed-method design. A separate analysis was conducted for each component: dose delivered, dose received: exposure and dose received: satisfaction.

2.5.1. Dose Received: Satisfaction (Qualitative Data)

The qualitative data was analyzed with the thematic analysis of Braun and Clarke.³⁷ Each interview was recorded and transcribed verbatim with the MAXQDA (version 20.0.7) software.⁴² Thematic analysis exists of six phases.³⁷ In the first phase, the researcher (DB) repeatedly read the transcript and listened to the audio data.^{37,43,44} The researcher also took notes of items of potential interest. The researcher moved to phase 2 when familiarization with the data was achieved. In this phase, the researcher started to analyze the data through generation of data codes.³⁷ Codes identified aspects of the data and related them to the research question. Phase 2 ended when the data was fully coded, and the codes were checked by a researcher from the main study. Phase 3 began with the search for themes.³⁷ The coded data was reviewed and areas of similarity were identified. The themes were written down in a thematic map to help explore relationships and patterns. In phase 4, the developed themes were reviewed in relation with the coded data and the entire data set.³⁷ In phase 5, the defined themes were named. The last phase described the findings in a paper.

2.5.2. Dose Delivered (Quantitative Data)

The quantitative data was analyzed using the Statistical Package for the Social Sciences (SPSS) (version 24).⁴⁵ For each component of the PSCP, a process indicator was developed by the research team. A process indicator measures the development of the process.⁴⁶ The process indicators in this study are the percentage of patients who received a component of the PSCP in order to gain understanding in how many patients received each component. The results were presented in a table and the analysis was done descriptively.^{47,48}

2.5.3. Dose Received: Exposure (Quantitative and Qualitative Data)

The collected qualitative data and quantitative data were compared with each other using the process indicators of the PSCP that were provided directly to the patients. However, one process indicator was added to measure if patients knew when they started with the PSCP. The process indicators are in Table 6. The information from the interviews about the PSCP was compared with the information within the quantitative data to analyze if the patients understood the information received within the PSCP. To compare these results, the data was presented in a case-by-variable meta-matrix.³² The patients were written in the rows and the quantitative and qualitative data were written in the columns.

2.6. Ethical Issues

The study protocol and procedures were approved by the Medical Ethics Committee. This study was conducted according to the principles of the Declaration of Helsinki (Version: 64th WMA General Assembly, Fortaleza, Brazil, October 2013) and in accordance with the

Medical Research Involving Human Subjects Act (WMO). There was no potential harm for participants. Although talking about end-of-life care can be considered burdensome for patients, these conversations should be regular practice, a statement that is supported by guidelines.³

2.6.1. Recruitment and Consent

Three times a week, departments' admissions records were screened for eligible patients by a research nurse. When the patient met the inclusion criteria, the treating physician provided the patient with written and oral information about the PSCP and obtained a written informed consent. Two weeks after the participants were discharged from the hospital, the participants received a house call from the palliative home-care nurse or hospital nurse of the transmural palliative team (TPT). The TPT exists of a palliative care doctor, palliative care general practitioner, spiritual caregiver and palliative home care and hospital nurses. A few days after the house call, the novice researcher (DB) made an appointment for the interview by phone with the participant. The researcher (DB) of this study was a clinical health science master's student who performed the interviews.

3. Results

In total, 22 patients met the inclusion criteria. Four patients dropped out of the study because they were not able to or did not want to participate. Six patients were approached for a semi-structured interview. Two patients declined because they felt sick or had no energy for the interview. In total, four patients completed the semi-structured interviews. In the end, no more interviews could be completed because of the COVID-19 virus in the Netherlands.

3.1 Social Demographic Characteristics

The patients were in the age range of 74 to 95 with a median age of 84. All patients had a Dutch ethnicity. More patients were male (61.1%) than female (38.9%) and most patients were married (38.9%) or widowed (33.3%). Furthermore, most patients currently live independently with home care (38.9%). See Table 3 about sociodemographic characteristics for more information.

-Table 3 approximately here-

3.2 Dose Received: Satisfaction (Qualitative Data)

The interviews were conducted at the patients' homes. For three interviews an informal caregiver was present. The researcher had no relation with the patients. The interviews

ranged approximately from 25 minutes to 60 minutes. No data saturation was found because of the small sample size. The main themes are presented in Table 4.

-Table 4 approximately here –

Theme 1: Different Expectations of the PalliSupport Conversations

Several patients reported different expectations of what the conversations about the PSCP would be. They mentioned that the goal, content and follow-up of the conversations were unclear. As a result, one patient mentioned the conversation focused too much on end-of-life care. He said he expected that they wanted to know about his experiences with the hospital.

Q1: *“Again, I got the idea that they wanted to know how I was treated in the hospital.”*
(Patient 4)

Furthermore, there was a misunderstanding for some about the definition of palliative care. It was expected that the conversations would be more practical, with a focus on daily life. However, it was experienced that the conversations focused more on medical care.

Q2: *“Practical and not medical. If they emphasize that the conversation is medical and ask where your interests are, then you can focus. Like talking about euthanasia, etc., support, medical support until the end.”* (Patient 2)

Q3: *“I was curious. I thought, maybe they will think about the situation I’m in right now. And how I will need care in the future. Home care, nursing or nursing home. Or something like that. I expected that would be the focus. But that was not the case.”* (Patient 2)

Theme 2: Changing Expectations in Hospital and at Home

One patient mentioned that he felt the need to hold the conversations in the hospital because he was feeling sick and thought he was going to die. However, when he got home he felt physically better than he did in the hospital. He mentioned that he does not need to talk about the end of his life anymore because he was feeling better. At home, he rather talked about the little things he could still do. As an example, he wanted to take a walk with some friends.

Q5: *“Back then I was more interested. Now the interest is less. Maybe because I was in a different environment. The hospital. Back then I said this can be a turning point, what will I do? Then I started looking for health care ... a nursing home, etc. Only it didn’t come that far.”* (Patient 2)

Theme 3: Different Perspective of Hospital Care

Two patients mentioned that the hospital will make you better and increase your health. They expected that going to the hospital would improve their health and were satisfied if they were feeling better when discharged from the hospital.

One patient didn't expect to talk about end-of-life care in the hospital because he was not under the impression that he was very sick.

Q7: "I think you're in the hospital to make someone better. Or not? I didn't get the idea I went to the hospital to get better." (Patient 4)

Theme 4: Hospital is the Right Place to Talk about Palliative Care

One patient mentioned it wasn't wrong to talk about palliative care in the hospital and had no further comments about the conversation.

Theme 5: Not Remembering the Conversations in the Hospital and at Home

Two patients couldn't remember their conversations in the hospital and at home. One patient mentioned it was difficult to focus and remember because of the many impressions and because of declining health.

Q10: "I think that if I can cooperate with something then I will, but I haven't really planned that in my mind. So, I forgot everything." (Patient 1)

Theme 6: Not Thinking about the End of Life

One patient said he knew that the end was coming, but that it was too hard to think about it.

Q11: "The end is coming. That is one thing that is sure and the more you worry, the more you have to think about it and the harder it gets. I think. So, I am like an ostrich. Burying my head in the sand." (Patient 2)

Another patient and caregiver didn't think about death and just wanted to live their lives without any complaints.

Q12: "We didn't think about it. We live, and hopefully soon, without pain. So, but the dead, I didn't think about it." (Patient 1)

Theme 7: Satisfied about Care

A caregiver of a patient mentioned that her mother really liked the personal attention and that the healthcare professionals took their time.

Q13: “Yeah I think, that she doesn’t understand you, but in the hospital in September a few times people came by and visited her. They were incredibly nice and she liked that very much. That was because of the attention. The personal attention and talking calm and friendly. Yes it is. That was it.” (Caregiver 3)

3.3 Dose Delivered (Quantitative Data)

Two weeks after being discharged, four patients passed away and no further data about these patients was collected. Data was collected from 15 patients until four weeks after discharge and from six patients 12 weeks after discharge. Hereafter, no other patient completed the PCSP because of the COVID-19 virus.

The implemented components ranged from 0% to 94.4% (n=17). The lowest component was that no district nurse was invited for a warm handover in the hospital. Reasons for not inviting the district nurse were that the patient had already gone home or the patient was not visited by or held discussions with the TPT in the hospital. The highest component was the percentage of GPs that received a written medical handover after discharge. The results are presented in Table 5. For some process indicators, reasons were described because the indicators were not conducted as planned. Reasons for not conducting the palliative care assessments were that the health condition of the patient didn’t allow it; the patient was already discharged from the hospital and the GP was not yet contacted and informed. Reasons for not having a formulated, individualized care plan: it didn’t go well, the health condition of the patient didn’t allow it, it was done by the GP, the patient already went home, the four dimensions of palliative needs were completed but no plan was made, the GP was not yet contacted and informed, or a proactive health care plan was already completed. Therefore, reasons that the patient didn’t receive a copy were that for 13 patients no care plan was formulated, and one patient dropped out of the study and went to the hospice. Moreover, reasons for not informing GP about the palliative care status were that the patient couldn’t remember the care pathway and became very emotional. Second, the palliative care status was not mentioned in the medical handover.

-Table 5 approximately here -

3.4 Dose Received: Exposure (Quantitative and Qualitative Data)

In total, four patients were included. The results are presented in Table 6. One patient thought that he had already participated for a year in the PSCP when in truth it was only for a few months. Two patients knew when it started but could not clearly remember the content of their conversations. One patient did not mention when the PSCP started. Three patients

remembered a conversation when asked if the preferred place of death was discussed. One patient said it was very clear and one patient did not remember the content of the conversation.

Furthermore, three patients did not mention if the TPT completed a palliative care assessment. One patient remembered a conversation, but no assessment was done.

All patients were visited by the TPT at home. Two patients remembered the conversation and one patient thought they were from the home care. One patient was contacted at home by the TPT, but this was not mentioned in the interview.

-Table 6 approximately here-

4. Discussion

The aim of this study was to explore patients' experiences with and perspectives on the PSCP in the palliative care phase and to provide insight into what extent the PSCP components, according to study protocol, were implemented. The main themes to explore the patients' experiences and perspectives were the different expectations of PSCP conversations, changing expectations in the hospital and at home, the different perspectives of what hospital care constitutes, the factor of the hospital as the right place to talk about palliative care, not remembering the conversations in the hospital and at home, not thinking about end-of-life care and satisfaction with the received care. Furthermore, the extent of the implemented components, according to study protocol, ranged from 0.0% until 94.4%. The lowest component was that no district nurse was invited for a warm handover in the hospital and the highest component was the percentage of GPs that received a written medical handover after discharge. Moreover, from the compared qualitative and quantitative data, the main outcome was that some patients remembered the process indicators of the PSCP, but other patients had too much on their mind and couldn't remember the conversations or the content of the conversations.

It is interesting that patients did not remember the content or the conversations of the PSCP. However, the patients mentioned they were busy with their own health and their changing environments so they forgot many things. Furthermore, it should be taken into consideration that the PSCP focused more on organizational components than components directly experienced by patients.

Patients also mentioned that it wasn't the right time to have conversations about end-of-life care. This was also mentioned in other studies because health care professionals experienced difficulties in recognizing the right time to make referrals, they lacked disease-specific expertise or lacked knowledge of the advantages of a timely referral.^{15,16,49,50} In this study, it should be taken into account that the PSCP is a new intervention and the health

care professionals have to get used to working with the PSCP and having end-of-life care conversations.^{15,16,49,50} Moreover, the patients in this study mentioned that they would have rather talked about practical information instead of medical information. A similar study described how patients preferred a conversation that focused on how to live with the fact that they will die and preferred to hear what they can do in their present state.⁵⁰ When the time comes, they want to think about what they need to have arranged or if they can still live at home.

When focusing on the implemented components, it is interesting that the lowest component is 0.0% and the highest is 94.4%. No warm handovers were completed because the patient had already gone home (thus there was no time left for a warm handover), the patient was not yet visited by or had discussions with the TPT in the hospital. Other studies have shown that difficulties were experienced because of a lack of time.^{51,52} Other reasons were due to unclear needs, strict privacy laws and different work shifts. However, this study only focused on three components of the process evaluation, thus it doesn't provide enough insight into the barriers and fidelity of the implementation of the PSCP.

The highest implemented component was that 94.4% of GPs received a written medical handover after discharge. It is remarkable that only 44.4% of GPs received the palliative care status of the patient because the palliative care status was not mentioned in the medical handover or the patient could not remember the PSCP and became very emotional. It is important to further research why the palliative care status was not mentioned in the medical handover for which there could be different causes.⁵³

The strength of this study is that it has a mixed-method design because it combines qualitative and quantitative results and enables different perspectives of the PSCP.

Moreover, this study creates insight into how the PSCP was conducted in the early stages. A limitation of this study was that the interviews were conducted by a novice researcher with a lack of experience conducting interviews, which may have influenced the depth of the interview. Furthermore, a recall bias can be present because the first conversation about the PSCP was five months ago and the patient can have problems recollecting information. However, some patients mentioned that they didn't remember the conversations because of the different environment and their declining health. Moreover, this study had a small sample size and no data saturation was confirmed. This can influence the depth and quality of results.

In conclusion, the experiences and perspectives of the patients were variable. Some patients were positive, others mentioned they had different expectations of the conversations and a few patients did not remember the conversations or content of the PSCP. Furthermore, there was a large difference into the extent each component was implemented. This study gives a first overview of the experiences and perspectives of patients and the implemented

components of the PSCP. Furthermore, insight is created in the process of implementation and these results can support further implementation. However, it should be taken into consideration the importance of fitting the wishes of patients and finding the right time for end-of-life care conversations with the patients. Implications for further studies are in-depth research on the implemented components, an exploration of the experiences and perspectives of health care professionals and the usage of a larger sample size.

5. References

1. RIVM. Bevolking→Cijfers & Context→Vergrijzing [Internet]. 2019 [cited 2019 Apr 24]. Available from: <https://www.volksgezondheidenzorg.info/onderwerp/bevolking/cijfers-context/vergrijzing#node-totaal-aantal-ouderen>
2. Ranglijst doodsoorzaken op basis van sterfte | Volksgezondheidenzorg.info [Internet]. [cited 2019 Dec 12]. Available from: <https://www.volksgezondheidenzorg.info/ranglijst/ranglijst-doodsoorzaken-op-basis-van-sterfte>
3. IKNL/Palliactief. Kwaliteitskader palliatieve zorg Nederland. 2017.
4. WHO | WHO Definition of Palliative Care [Internet]. [cited 2020 Mar 1]. Available from: <https://www.who.int/cancer/palliative/definition/en/>
5. Davelaar L. Cijfers palliatieve zorg | Kennisplein Zorg voor Beter [Internet]. 2016 [cited 2019 Oct 18]. Available from: <https://www.zorgvoorbeter.nl/palliatieve-zorg/cijfers>
6. Wahid AS, Sayma M, Jamshaid S, Kerwat D, Oyewole F, Saleh D, et al. Barriers and facilitators influencing death at home : A meta-ethnography. *Palliat Med.* 2018;32(2):314–28.
7. D’Astous V, Abrams R, Vandrevalla T, Samsi K, Manthorpe J. Gaps in understanding the experiences of homecare workers providing care for people with dementia up to the end of life: A systematic review. *Dementia [Internet]*. 2017 Jan 1 [cited 2019 Apr 6];1471301217699354. Available from: <http://journals.sagepub.com/doi/10.1177/1471301217699354>
8. Green E, Knight S, Gott M, Barclay S, White P. Patients ’ and carers ’ perspectives of palliative care in general practice : A systematic review with narrative synthesis. *Palliat Med.* 2018;32(4):838–50.
9. Chaudhry SI, Murphy TE, Gahbauer E, Sussman LS, Allore HG, Gill TM. Restricting Symptoms in the Last Year of Life A Prospective Cohort Study. 2019;8093(16):1534–40.
10. Buurman B. Functieverlies ouderen bij acute opname in ziekenhuis. *Ned Tijdschr Geneeskd.* 2015;159(A8185).
11. Verhaegh et al. K. Transitional care interventions prevent hospital readmissions for adults with chronic illnesses. *Heal Aff.* 2014;33(9):1531–9.
12. Reichardt LAA, van Seben R, Van der Schaaf M, Engelbert RHH, Bosch JA, Buurman B. Unravelling the potential mechanisms behind hospitalization-associated disability in older patients; the hospital-Associated disability and impact on daily life (Hospital-ADL) cohort study protocol. *BMC Geriatr.* 2016;16(59).
13. Claessen SJF, Ehteld AL, Schweitzer BPM, Donker GA, Deliens L. GPs’ recognition of death in the foreseeable future and diagnosis of a fatal condition: a national survey. *BMC Fam Pract.* 2013;14(104).
14. De Korte-Verhoef et al. M. Reasons for hospitalisation at the end of life: differences between cancer and non-cancer patients. *Support Care Cancer.* 2014;22(3):645–52.
15. Broom A, Kirby E, Good P, Wootton J, Adams J. Specialists’ experiences and perspectives on the timing of referral to palliative care: A qualitative study. *J Palliat Med.* 2012;15(11):1248–53.
16. Schofield P, Peter MC. ‘Would you like to talk about your future treatment options?’ discussing the transition from curative cancer treatment to palliative care.

17. Donker G. Gewenste plaats van overlijden tijdig bespreken. *Huisarts Wet.* 2010;53(5).
18. Huijberts S, Buurman BM, Rooij SE De. End-of-life care during and after an acute hospitalization in older patients with cancer , end-stage organ failure , or frailty : A sub-analysis of a prospective cohort study. *Palliat Med.* 2016;30(1):75–82.
19. Heyland D. Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA intern Med.* 2013;173(9):778–87.
20. De Korte-Verhoef M, Schweitzer B, Francke A, Onwuteaka-Philipsen B, Deliens L. End-of-life hospital referrals by out-of-hours general practitioners: a retrospective chart study. *BMC Fam Pract.* 2012;13(89).
21. Hesselink et al. G. Organizational culture: an important context for addressing and improving hospital to community patient discharge. *Med Care.* 2013;51(1):90–8.
22. BM B et al. Geriatric conditions in acutely hospitalized older patients: prevalence and one-year survival and functional decline. *PLoS One.* 2011;6(11):e26951.
23. De Korte-Verhoef et al. M. How could hospitalisations at the end of life have been avoided? A qualitative retrospective study of the perspectives of general practitioners, nurses and family carers. *PLoS One.* 2015;10(3).
24. de Korte-Verhoef M, Schweitzer B, Francke A, Onwuteaka-Philipsen B, Deliens L. Burden for family carers at the end of life; a mixed-method study of the perspectives of family carers and GPs. *BMC Palliat Care.* 2014;13(16).
25. Flierman I, Buurman BM, Willems DL, Laros MMI M. PalliSupport: Visiedocument. 2018;1–21.
26. Buurman B, Willems D. Research protocol: Pallisupport, a transitional care pathway for elderly patients at the end of life. 2018;(september). Available from: <http://web.b.ebscohost.com.ezp2.lib.umn.edu/ehost/pdfviewer/pdfviewer?sid=00384591-098f-4f0e-a2f9-d32949cdde6e%40sessionmgr107&vid=1&hid=123>
27. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M, et al. Developing and evaluating complex interventions : new guidance. *BMJ.* 2008;337:a1655.
28. Moore G, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions UK Medical Research Council (MRC) guidance.
29. Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions: Medical Research Council guidance. [cited 2019 Nov 27]; Available from: <http://www.bmj.com/>
30. Craig P. Developing and evaluating complex interventions [Internet]. [cited 2020 Apr 19]. Available from: www.mrc.ac.uk/complexinterventionsguidance
31. Moore J, Mascarenhas A, Bain J, Straus S. Developing a comprehensive definition of sustainability. *Implement Sci.* 2017;12:110.
32. Polit F, Beck C. Designing and conducting mixed methods studies to generate evidence for nursing. In: *Nursing research: Generating and assessing evidence for nursing practice.* 10th ed. Wolters Kluwer; 2017. p. 576–622.
33. Creswel JH, Clark VLP. *Designing and conducting mixed methods research.* 3rd ed. SAGE Publications; 2018. 492 p.
34. Metzelthin SF, Daniëls R, van Rossum E, Cox K, Habets H, de Witte LP, et al. A nurse-led interdisciplinary primary care approach to prevent disability among community-dwelling frail older people: A large-scale process evaluation. *Int J Nurs*

- Stud. 2013;50(9):1184–96.
35. PaTZ. Stel de 'Surprise Question' [Internet]. [cited 2020 Apr 12]. Available from: <https://www.patz.nu/images/downloads/surprisequestion.pdf>
 36. IKNL. Over palliatieve zorg - IKNL [Internet]. [cited 2020 Apr 12]. Available from: <https://www.iknl.nl/palliatieve-zorg/over-palliatieve-zorg>
 37. Braun V, Clarke V. *Successful Qualitative Research*. Carmichael M, editor. SAGE Publications Ltd; 2013.
 38. Zwakman M, Jabbarian LJ, Delden JJM Van, Heide A Van Der, Korfage IJ, Pollock K, et al. Advance care planning : A systematic review about experiences of patients with a life-threatening or life-limiting illness. *Palliat Med*. 2018;32(8):1305–21.
 39. Ke L, Huang X, Hu W, O'Connor M, Lee S. Experiences and perspectives of older people regarding advance care planning : A meta-synthesis of qualitative studies. *Palliat Med*. 2017;31(5):394–405.
 40. Cowley A, Evans C, Bath-Hextall F, Cooper J. Patient, nursing and medical staff experiences and perceptions of the care of people with palliative esophagogastric cancer: a systematic review of the qualitative evidence. *Joanna Briggs Inst*. 2016;134–66.
 41. Pask S, Pinto C, Bristowe K, van Vliet L, Nicholson C, Evans CJ, et al. A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals. *Palliat Med*. 2018;32(6):1078–90.
 42. VERBI GmbH. MAXQDA. 2020.
 43. Holloway I, Gavin K. *Qualitative Research in Nursing and Healthcare*. 4th ed. John Wiley en Sons, Ltd; 2017.
 44. Boeije H. *Analysis in Qualitative Research*. SAGE Publications Ltd; 2010.
 45. SPSS Software - Netherlands | IBM [Internet]. [cited 2020 Apr 17]. Available from: <https://www.ibm.com/nl-en/analytics/spss-statistics-software>
 46. New Zealand Qualifications Authority. Process Indicators » NZQA [Internet]. [cited 2020 Apr 17]. Available from: <https://www.nzqa.govt.nz/providers-partners/external-evaluation-and-review/evaluation-indicators-for-itos/process-indicators/>
 47. Griffin SF, Wilcox S, Ory MG, Lattimore D, Leviton L, Castro C, et al. Results from the Active for Life process evaluation: program delivery fidelity and adaptations. [cited 2020 Apr 17]; Available from: <https://academic.oup.com/her/article-abstract/25/2/325/668833>
 48. Robbins LB, Ling J, Kilicarslan Toruner E, Bourne KA, Pfeiffer KA. Examining reach, dose, and fidelity of the 'Girls on the Move' after-school physical activity club: a process evaluation. 2016;
 49. Melvin CS, Oldham L. When to refer patients to palliative care: Triggers, traps, and timely referrals. *J Hosp Palliat Nurs*. 2009;11(5):291–301.
 50. Back AL, Trinidad SB, Hopley EK, Edwards KA. Reframing the goals of care conversation: 'We're in a different place'. *J Palliat Med*. 2014;17(9):1019–24.
 51. Flierman I, van Seben R, van Rijn M, Poels M, Buurman BM, Willems DL. Health Care Providers' Views on the Transition Between Hospital and Primary Care in Patients in the Palliative Phase: A Qualitative Description Study. *J Pain Symptom Manage* [Internet]. 2020; Available from: <https://doi.org/10.1016/j.jpainsymman.2020.02.018>

52. Campbell Britton M, Hodshon B, Chaudhry SI. Implementing a Warm Handoff between Hospital and Skilled Nursing Facility Clinicians. *J Patient Saf.* 2019;15(3):198–204.
53. Michie S, van Stralen MM, West R. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implement Sci* [Internet]. 2011 Apr 23 [cited 2020 May 31];6(1):42. Available from: <http://implementationscience.biomedcentral.com/articles/10.1186/1748-5908-6-42>

Figures and tables

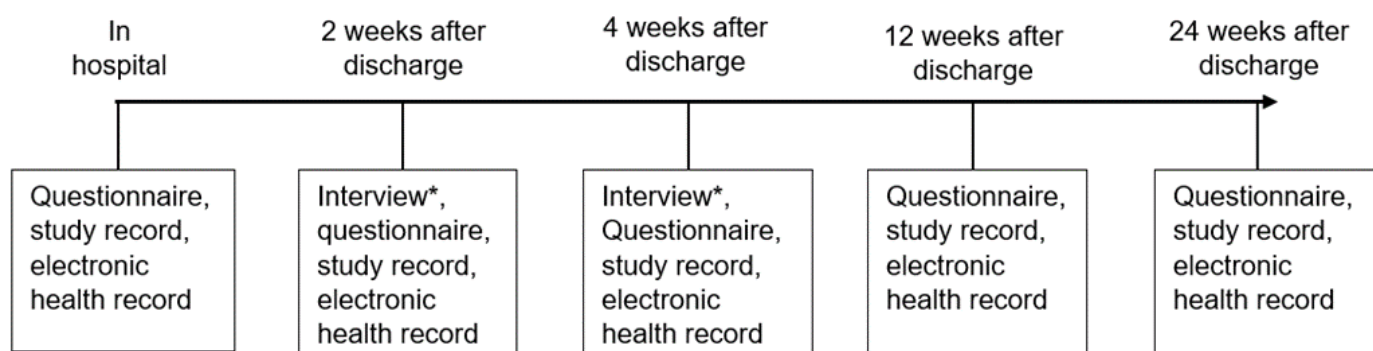
Table 1 Components of the PalliSupport care pathway

Approach to care	When patients are admitted to the hospital, the treating physician contacts the general practitioner (GP) to inform about the PalliSupport care pathway.
Conversation about palliative care	The treating physician introduces the transmural palliative team (TPT). TPT will have an advanced care planning (ACP) conversation with the patients and if possible, the informal caregiver of the patient is also invited. The goal of ACP is to provide appropriate palliative care and be in line with the wishes of the patients. Within this conversation the patients' preferred place of death is discussed during ACP conversations.
Palliative care assessment	TPT will assess the needs in palliative care and formulates an individualized care plan. The needs are assessed along four dimensions: physical, psychological, social and spiritual needs. The TPT consists of a palliative doctor, palliative general practitioner, spiritual caregiver and palliative home care and hospital nurses.
Individualized care plan	TPT and/or treating physician formulates an individualized care plan.
Multidisciplinary conversation	The GP and district nurse are invited for a multidisciplinary team (MDT) meeting at the hospital to discuss the patients' situation.
Discharged from hospital	TPT and/or treating physician contacts GP prior to discharge. The district nurse is invited for a warm handover in the hospital. The patient receives a copy of the care plan when discharged from the hospital and a medical handover and summary will be sent to the GP within 24 hours.
Follow-up	The TPT will visit the patient at home during a monitoring visit. If necessary, the burden of informal care is assessed.

Table 2 Measurement of each component of the mixed-method design

Component process evaluation	Question	Data	Measurement
Dose Received (satisfaction)	What are the experiences and perspectives of the patients with the PalliSupport care pathway?	Qualitative	Thematic analysis. Results in themes and quotes.
Dose Delivered	How many components according to the study protocol of the PalliSupport care pathway have been delivered to the patients?	Quantitative	Percentage of how many patients followed each component according to the study protocol of the PalliSupport care pathway.
Dose Received (exposure)	Did the patients understand the information that was implemented within the PalliSupport care pathway?	Qualitative and Quantitative	Comparing the results of the qualitative data and quantitative data of the participants that followed the PalliSupport care pathway and were interviewed.

Figure 1 Overview of data collection



*: The interview was conducted by the main researcher of this study. The other measurements were collected from the main study. Furthermore, the interview was conducted between 2 weeks and 4 weeks after discharge.

Table 3 Sociodemographic characteristics

Sociodemographic characteristics	Patients (N=18) n(%)
Age in years, median (range)	84 (74-95)
Gender	
- Male	11 (61.1%)
- Female	7 (38.9%)
Marital status	
- Married	7 (38.9%)
- Divorced	1 (5.6%)
- Single	2 (11.1%)
- Widowed	6 (33.3%)
- Not mentioned	1 (5.6%)
- Other	1 (5.6%)
Living arrangement	
- Independent, alone	3 (16.7%)
- Independent with home care	7 (38.9%)
- Independent with others	3 (16.7%)
- Independent with others and home care	3 (16.7%)
- Nursing home	2 (11.1%)

Table 4 Themes and Quotes

Themes	Supporting quotes
Different expectations of PalliSupport conversations	<p>Q1: "Again, I got the idea that they wanted to know how I was treated in the hospital." (Patient 4)</p> <p>Q2: "Practical and not medical. If they emphasize that the conversation is medical and ask where your interests are, then you can focus. Like talking about euthanasia, etc., support, medical support until the end." (Patient 2)</p> <p>Q3: "I was curious. I thought maybe they will think about the situation I'm in right now and how I will need care in the future. Home care, nursing or nursing home. Or something like that. I expected that would be the focus. But that was not the case." (Patient 2)</p>
Changing expectations in hospital and at home	<p>Q4: "Now she is home again and I am wondering. In the further, she will have a physically decrease ... is this still possible? Living independent." (Caregiver 3)</p> <p>Q5: "Back then I was more interested. Now the interest is less. Maybe because I was in a different environment. The hospital. Back then I said this can be a turning point, what will I do? Then I started looking for health care, a nursing home, etc. Only it didn't come that far." (Patient 2)</p>
Different perspective of hospital care	<p>Q6: "Yeah I thought ... I was more thinking about what can we do to make you better instead of ... how do you think about the dead." (Patient 4)</p> <p>Q7: "I think you're in the hospital to make someone better. Or not? I didn't get the idea I went to the hospital to get better." (Patient 4)</p>
Hospital is the right place to talk about palliative care	<p>Q8: "Yeah it was not wrong. No comments." (Patient 2)</p>
Not remembering the conversations in the hospital and at home	<p>Q9: "No, no, no. I can't, it is that my sister mentioned it, but I couldn't remember." (Patient 1)</p> <p>Q10: "I think that if I can cooperate with something then I will, but I haven't really planned that in my mind. So, I forgot everything." (Patient 1)</p>
Not thinking about end-of-life	<p>Q11: "The end is coming. That is one thing that is sure and the more you worry, the more you have to think about it and the harder it gets. I think. So, I am like an ostrich. Burying my head in the sand." (Patient 2)</p> <p>Q12: "We didn't think about it. We live, and hopefully soon, without pain. So, but the dead, I didn't think about it." (Patient 1)</p>
Satisfied about care	<p>Q13: "Yeah I think, that she doesn't understand you, but in the hospital in September a few times people came by and visited her. They were incredibly nice and she liked that very much. That was because of the attention. The personal attention and talking calm and friendly. Yes, it is. ... That was it." (Caregiver 3)</p> <p>Q14: "Yeah they already knew me. From the year before. So that was really easy." (Patient 2)</p>

Table 5 Percentage completed components of PalliSupport

Process indicators of PalliSupport	Completed n (%)
In hospital	n=18
Patient's preferred place of death is discussed.	12 (66.7%)
TPT performs a complete palliative care assessment.	9 (50%)
TPT and/or treating physician formulates an individualized care plan.	4 (22.2%)
The patient's case is discussed at the MDT meeting.	6 (33.3%)
Patient receives a copy of individualized care plan prior to discharge.	3 (16.7%)
GP receives written medical handover after discharge.	17 (94.4%)
GP is informed about palliative status of patient.	8 (44.4%)
District nurse is invited for a warm handover in the hospital.	0 (0%)
The complexity of the patient's palliative care situation is assessed using the new working method (color coding green – orange – red).	9 (50%)
Registered symptom burden in hospital.	12 (66.7%)
2 weeks after discharge	n= 15
TPT visits the patient at home during a monitoring visit.	5 (29.4%)
TPT contact patients at home.	1 (5.9%)
Registered symptom burden.	7 (41.2%)
The patients' case is discussed at the MDT meeting.	2 (11.8%)
4 weeks after discharge	n= 15
TPT visits the patient at home during a monitoring visit.	4 (25%)
TPT contact patients at home.	0 (0%)
Registered symptom burden.	7 (43.8%)
The patients' case is discussed at the MDT meeting.	0 (0%)
12 weeks after discharge	n= 6
TPT visits the patient at home during a monitoring visit.	0 (0%)
TPT contact patients at home.	0 (0%)
Registered symptom burden.	4 (66.7%)
The patients' case is discussed at the MDT meeting.	0 (0%)
Other	
Home visits according to color coding.	8 (88.9%)
Included informal caregivers.	4 (22.2%)
The patient's case is discussed at least once at the MDT meeting.	6 (33.3%)
TPT visits the patient at home during a monitoring visit at least once.	9 (50%)
TPT contact patients at least once at home.	2 (11.1%)
Completely conducted consultations according to care pathway.	8 (44.4%)
Total registered consults in hospital done by TPT.	15 (83.3%)

Table 6 Meta-matrix Comparing Qualitative and Quantitative Results

Case	Patient started with PalliSupport	Narrative
1	2-01-2020	19 th of December in the hospital and 26 th of December discharged from the hospital.
2	24-01-2020	Not mentioned.
3	25-09-2020	No, but in the beginning she had ... somewhere in September it started.
4	24-12-2019	It was a long time ago ... I think a year.
Case	Patient's preferred place of death is discussed during ACP conversations	Narrative
1	Yes, Home	Someone did come from your organization. The one that took the interview. But yeah, I can remember. But I don't know what she asked anymore.
2	No, not discussed	Yes, with one of the doctors first. I liked him, but again I got the idea he wanted to know what I thought of the hospital.
3	Yes, other.	It was clear, concerning her situation, how it was.
4	Yes, Hospice	No, can't remember.
Case	TPT performs a complete palliative care assessment	Narrative
1	No, patient was already gone. Done at home visit.	Not mentioned.
2	No, first contact with general practitioner.	At the day of discharge, we had a conversation with ... what was the name again of that woman? She has been here before. She knows everything about us on the screen.
3	Yes	Not mentioned.
4	Yes	Not mentioned.
Case	TPT visits the patient at home during a monitoring visit	Narrative
1	Yes, after 2 weeks	There was one lady with fizzy hair for an interview about the health care. For the health care dossier.
2	Yes, after 2 weeks	That one interview. It was a little bit focused I found. It was a little bit talking to the side if you die. It was more depressing than positive.
3	Yes, after 2 weeks	No
4	Yes, after 4 weeks	It was more additional information. Not more.
Case	TPT contact patients at home	Narrative
1	No	Not mentioned.
2	No	Not mentioned.
3	Yes once, after 2 weeks	Not mentioned.
4	No	Not mentioned.