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A proposed model for the early integration of palliative home care for advanced cancer patients in Belgium

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CONTENT

Chapters 2-6 are based on the following publications

Chapter 2:

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Chapter 3:

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Chapter 4:

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Chapter 5:

Dhollander N, Smets T, De Vleminck A, Lapeire L, Pardon K, Deliens L. Is early integration of palliative home care in oncology treatment feasible and acceptable? A phase 2 pre-post study in advanced cancer patients and their health care providers. (Submitted)

Chapter 6:

Dhollander N, Smets T, De Vleminck A, Lapeire L, Pardon K, Deliens L. Early enrollment of patients with active oncological treatment into palliative home care: lessons from a phase II trial. (Submitted)

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Part I:

General Introduction

Chapter 1:

General introduction

INTRODUCTION

Background

Symptom burden of cancer patients

The development of new possible anticancer treatments has increased exponentially during the last years[1–4]. New immune therapies have been introduced to standard chemotherapy, with working procedures and side-effects that differ from traditional anticancer treatments and with unpredictable outcome effects on prognosis and survival. We do know that the developments in treatments and cancer research are leading to an increase in the number of patients living with advanced cancer for several years and therefore recently caused a reshaping of cancer into a chronic disease[2–4]. In 2010, the World Health Organization (WHO) recognized cancer as one of the four major chronic illnesses together with diabetes, cardiovascular diseases and chronic respiratory diseases[5].

Patients diagnosed with an advanced cancer typically experience emotional and existential distress, as well as physical symptoms that might have an influence on their functioning and quality of life[6–8]. Common symptoms in patients with advanced cancer include fatigue, pain, weakness, lack of energy[9–11]. Several studies show that in the life-prolonging phase symptoms and problems that are core issues of palliative care can be present and typically increase as the terminal phase or death approaches[12,13]. This confirms a needs-based model in which palliative care needs can be present from diagnosis on[14].

Oncologists have been and are still responsible for guiding patients in treatment decisions, often focusing on the use of treatments to control disease progression[12]. The psychological, social and existential needs of patients with cancer are less often addressed and treated by their oncologists[9,15–17]. Due to the increasing chronic character of the disease, caring for cancer patients will require the combination of tumor-directed therapies and patient-centered approaches[18]. Palliative care is a patient-centered approach that aims to achieve the best quality of life of patients and their family caregivers with life-limiting diseases and addresses a range of care dimensions including physical, psychological, social and existential issues[19]. To mitigate the needs of advanced cancer patients that are often undertreated by oncologists, several guidelines[19–21] recommend that palliative care is initiated early, ideally concurrent with curative or life-prolonging treatments, and becomes gradually more important as death approaches.[14,22] This concept wherein palliative care is provided concurrent with anticancer treatment has been referred as "early palliative care" or "early integrated palliative care" or "early integration of palliative care".[23,24]

Shifting to a new model of palliative care

The new insights on existing palliative care needs early in the disease trajectory of advanced cancer patients and the benefits of early palliative care caused a shift in the view on palliative care. In the old model, palliative care is seen as a sharp transition from being curative or receiving life-prolonging treatment to becoming terminally ill when close to death[14,22]. In the new model, palliative care starts at diagnosis of an advanced cancer or another life-limiting disease and as the disease worsens, the impact and use of palliative care according to the needs of the patient becomes increasingly important. The new model of care requires that oncology teams and palliative care providers collaborate with each other to provide continuity of care to not only patients, but also family caregivers[14].

As defined by the WHO definition of palliative care and recommended by the American Society of Clinical Oncology (ASCO), the Multinational Association of Supportive Care in Cancer (MASCC), the European Society for Medical Oncology (ESMO) and the European Association for Palliative Care (EAPC), the new model of care wherein palliative care is available during and after disease-modifying therapy has beneficial effects on the quality of life of patients and family caregivers and needs to be the new standard of patient-centered care.[19,21,24,25] However, studies show that especially the old model of palliative care is still used in the care for patients with a chronic illness. A study on palliative care use in four European countries shows that specialized palliative care teams are only introduced 15 days before death in Belgium to 30 days before death in Italy and a recent survey in Belgium shows that patients with advanced cancer were referred to palliative care only 16 days prior to death[26,27].

Existing evidence for early palliative care

Before the start of this PhD trajectory, results of three randomized controlled trials (RCTs) were published showing positive evidence for the added value of the new palliative care model in which specialized palliative care – i.e. palliative care provided by a multidisciplinary palliative care team – was integrated into oncology care[28,29]. These RCTs formed the basis for the intervention model in this PhD dissertation and are therefore described below in detail.

Bakitas et al.[30] designed the ENABLE II (Education, Nurture, Advise, Before Life Ends) study, a randomized controlled trial to test a telephone-based nurse-led palliative care intervention with a psychoeducational approach which was delivered concurrent with active oncological treatment. They tested the intervention model in a sample of 322 advanced cancer patients and found a significant improvement in mood and quality of life. Importantly, no multidisciplinary palliative care team was involved in the intervention.

The study of Temel et al.[31] is seen as a milestone in the shift towards early palliative care. The study showed that early introduction of palliative care improved the quality of life, reduced symptom burden and increased survival in a sample of 151 newly diagnosed lung cancer patients. This intervention consisted of monthly consultations with a member of the palliative care team which consisted of palliative care physicians and a palliative care nurse. The consultations were structured by the National Consensus Project for Quality Palliative care focusing not only on symptom management, but also on themes like illness understanding, religion and spirituality, care preferences and coping.

Third, Zimmermann et al.[32] tested a similar model in which routine visits were installed monthly with structured symptom assessment in a sample of patients with mixed cancer diagnoses and a prognosis of approximately six months to two years. This study showed positive effects on quality of life and symptom burden, and the intervention group was more satisfied with care compared with the control group.

During the development phase of the EPHECT intervention, a trial designed by Vanbutsele and colleagues of our research group was tested in a sample of 186 advanced cancer patients in Belgium. The intervention[33] – consisting of four major components: palliative care consultations by a nurse of the palliative care team, systematic needs assessment, referral and training – showed beneficial effects on the quality of life of patients and was therefore also used as a reference in developing the EPHECT intervention[34].

The heterogeneity in study outcomes, study population and components of the interventions can be seen as a limitation in research on early palliative care. However, all trials showed a positive effect on different outcomes and it seems that several common components are important in reaching significant benefits of integrated palliative care. Following key components have formed the base for the developed intervention in this dissertation: 1) regular consultations by a member of the palliative care team, 2) semi-structured consultations with a focus on both symptom management and psychosocial care, and 3) education for involved health professionals.

Importantly, three of these interventions were developed for advanced patients cared for in the hospital setting[31,32,34] and one in the outpatient setting[30]. None of the trials published before the start and during the development phase of the EPHECT intervention were developed focusing on specialized palliative care provided in the home setting.

Relevance of this work

What about early palliative home care?

Research shows that the number of people eligible for receiving palliative care is rising and that the majority of those people prefers to receive this care at home[35–39]. Most of the patients who prefer to be cared for at home, also prefer to die at home[35,40]. Research indicates that being able to be cared for at home improves the wellbeing of patients and reduces healthcare costs and aggressive treatment at the end of life[41,42]. However, a recent cross-national study shows that only 18-46% of advanced cancer patients in 9 European countries died at home[43]. Recently, policy makers are focusing on promoting the integration of community palliative care services in general and specialist care for people with life-limiting illnesses by developing supportive measures to reduce the possible high costs of palliative home care[44].

Palliative home care teams provide specialized palliative care to patients and family caregivers at home. They are multidisciplinary oriented consisting of palliative care nurses, palliative care physicians and sometimes a psychologist. The palliative home care team has an advisory and mentoring function to patients, but also to general practitioners and nurses caring for the patient at home, and offers its expertise in pain therapy, symptom control, palliative care and psychosocial support.[45,46] Research shows that patients who received the support of such a palliative home care team had reduced symptom burden and increased chance of dying at home compared with patients who received usual care[47]. Other studies described other positive effects such as increased patient satisfaction and quality oy life, symptom improvement, fewer hospitalizations at the end of life, and a higher chance of dying at home[48,49]. For these reasons, palliative home care teams might become more important in providing early palliative care.

Palliative home care in Belgium

Palliative home care teams in Belgium can be involved by everyone, including the patients and family caregivers. However, as described in the Belgian law, the GP always has to give permission. In the job description of the palliative home care teams is described that they have to fulfil the role of palliative expert and that they need to give their expertise and support to primary and secondary palliative care providers, such as the general practitioner, the oncologist, etcetera. In theory, the palliative home care teams should only be contacted in complex care situations to give support to other professional caregivers in providing palliative care to patients. The Belgian system is therefore a combination of generalist and specialist palliative care, in which specialist palliative care should be seen as an expertise that can be consulted if generalist palliative care providers are confronted with complex care situations.

Palliative home care in Belgium is organized by 15 regional teams which support professional caregivers in the home context. They also support general practitioners (GPs) in their coordinating role by giving advice, doing home consultations and arranging multidisciplinary meetings[50]. The composition of the teams depends on the number of inhabitants in the region, but the minimum is two fulltime palliative care nurses, one palliative care physician (four hours a week) and one part-time administrative employee[51].

Recent studies in Belgium have demonstrated that the median period of referral to palliative care for cancer patients is 15 to 20 days before death[26,27]. Although the use of outpatient palliative care increases, data from 2014 show that 60% of all care trajectories of the palliative home care teams in Belgium last less than 30 days, only 18% last longer than 90 days and only 9% longer than 180 days[52]. These data show that the teams are still introduced often late in the disease trajectory, and that there is a need for intervention models to support palliative home care teams in being involved earlier in an advanced cancer disease trajectory.

Why focusing on and integrating specialized palliative home care?

Professional caregivers working in palliative home care teams are more familiar with the home context of the patient than palliative care professionals working in the hospital. Hence, patients can be cared for in their own context in optimal circumstances surrounded by those close to them. Furthermore, earlier in the disease trajectory, the palliative home care team has to spend less time on symptom management which is provided by the oncology team and the general practitioner. This creates more time to focus on supporting the general practitioner in the coordination of care, providing holistic care and giving expert advice to primary caregivers in providing generalist palliative care which may avoid unnecessary treatments or hospitalizations[53–55].

General practitioners are fulfilling an important role in the care for a patient, are seen as the central coordinator of care and have to give permission to palliative home care teams to support patients. However, according to the results of a study focusing on the attitudes of healthcare professionals towards collaboration in palliative home care, general practitioners do see the coordination of care as part of their job, but they find it a demanding and time-consuming task to do this alone[55]. Furthermore, too often the contact between patients and their GP weakens from the moment patients start with anticancer treatment in the hospital and the contact has to be renewed when treatment options are no longer benefiting and existing[56].

Because the majority of patients wants to be cared for at home and prefers to die at home[36–39,41], it is important that continuity of care can be guaranteed between the home and the hospital setting. However, because GPs are often not involved during active oncological treatment of their patients, this continuity of care to the home setting is often lacking. The need for interdisciplinary collaboration might cause confusion about responsibilities and task descriptions of the different disciplines[57]. Previous research shows that a lack of clear task descriptions and not knowing whom to address for certain problems are indeed seen as important barriers to interdisciplinary collaboration[24,55,58].

In current practice, they are often involved late to solve problems in acute situations because primary and secondary palliative caregivers are currently not trained enough to provide generalist palliative care. This leaves no time and space to fulfill their role as palliative expert as is described in their job description[50,60]. If palliative home care is involved earlier in a disease trajectory, the nurses of the PHC team have more time to focus on supporting the GP in the coordination of care and to make the bridge between healthcare professionals in the hospital and in the home setting which can facilitate continuity of care between the oncology setting and the palliative professionals[59,60].

Study objectives

The overall objective of this dissertation is to develop and evaluate a new model of early integration of palliative home care in standard oncological treatment (hereafter called EPHECT intervention) in Flanders, Belgium, with the aim of improving the quality of life of and quality of care for patients with advanced cancer.

The objective can be divided into two scientific aims.

The first aim is the *development* of a model to integrate palliative home care early in standard oncological treatment for patients with cancer in an advanced stage.

Specific objectives are:

1. To gather information on the current healthcare context by gaining insight into differences between early and late involvement of palliative home care and the effect on existing working procedures and skills as perceived by palliative home care teams,
2. To examine potential barriers for early palliative home care in standard oncology treatment in Flanders, Belgium as perceived by palliative home care teams,
3. To use these results to develop a new and potentially feasible, acceptable and effective integration model.

The second aim is to *implement and evaluate* the newly developed intervention model in a phase II study to prepare for a large phase III randomized controlled trial.

Specific objectives are:

4. To assess the feasibility and acceptability of the study procedures (e.g. recruitment, inclusion criteria),
5. To assess the feasibility and acceptability of the components of the EPHECT intervention, according to patients, family caregivers and healthcare professionals,
6. To explore preliminary effectiveness of the EPHECT intervention on the quality of life of patients and family caregivers and effects as perceived by patients, family caregivers and healthcare professionals,
7. To formulate recommendations for future care on when and how advanced cancer patients should be enrolled into palliative care.

Methods

To reach the aims of this dissertation, the UK Medical Research council (MRC) Framework for developing and evaluating complex interventions was used as a methodological guidance[61,62]. The framework helps researchers to identify the core components of interventions, gives the opportunity of iteration between phases and allows a degree in flexibility or tailoring of the intervention. The key components of an intervention refer to the essential features that define an effective intervention and produce desired outcomes[63]. The MRC Framework distinguishes between four different phases: 1) intervention development, 2) feasibility and piloting of the intervention model, 3) evaluation and 4) implementation. These phases comprise the development and evaluation of an intervention model by selecting the core components based on theory and modelling (Phase 0-I), a phase 2 study to evaluate the feasibility, acceptability and preliminary effectiveness of the intervention model (Phase II), evaluating the intervention in a large-scale phase 3 randomized controlled trial (Phase III), and implementing the intervention over the long term (Phase IV).

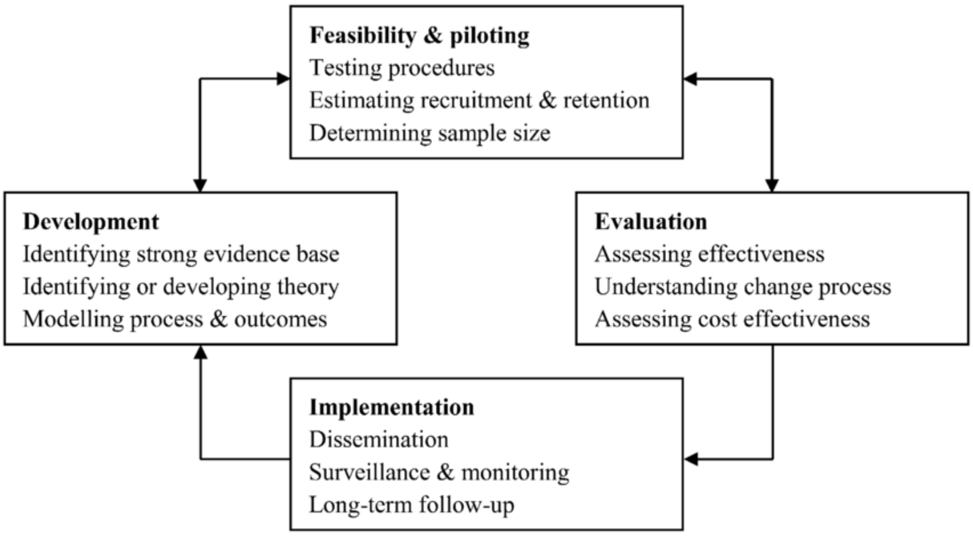

Figure 1 Medical Research Council Framework for complex interventions

The chapters in this dissertation describe a Phase 0-II study including the development, modelling and piloting of a complex intervention.

Phase 0: selecting the key components

We used two methods to obtain data and evidence for the development of the key components of the intervention, by gaining insight in evidence based practices in early palliative care research and in the healthcare context in which the intervention would be implemented.

1. Literature search

We performed a screening of the literature of existing and tested models of integration of palliative care into oncological care in different care settings and different countries. We limited our search to cluster-randomized controlled trials on integrated oncology care for people with advanced cancer and a prognosis of two years or less. We limited our search to studies that were published before the end of 2016, because the analyses of the literature search and the building of the intervention model started in 2017.

2. Focus groups with PHC teams

We conducted six focus groups with members of the PHC teams (n=51) to gain insight into differences between early and late involvement of PHC and into perceived barriers to early involvement. We also discussed a preliminary model for early integration based on the key components identified in the literature with the aim of reflecting on them and adapting them to the current working context of PHC in Flanders. As those teams have a coordinating role in organizing primary healthcare, they are ideally placed to provide contextual insights and essential information on how palliative care is structured and organized in the home setting and on how they work together with oncological services. We considered that the multidisciplinary character of the teams would provide us with data from caregivers with varying backgrounds and job roles, thus seeing the themes from different perspectives while stimulating reflection and discussion between professionals[64]**.**

Phase 1: modelling of intervention and development of the intervention materials

Based on the results of phase 0, we developed a preliminary intervention model to support the early integration of palliative home care into oncology care. During the modelling phase, we conducted semi-structured interviews with members of a PHC team and oncologists and used their feedback on the preliminary model. We also held 4 stakeholder workshops with representing patient groups, family caregivers, professionals working in palliative and primary care and with policy makers. The aim of this participatory approach was to explore the experiences of people with a serious illness and those surrounding them, and to brainstorm about how to further improve the intervention model[65]. The model was further refined at monthly meetings with the multidisciplinary research team consisting of psychologists, sociologists and a medical oncologist.

Phase 2: evaluating the newly developed intervention in a pre-post phase 2 trial on feasibility, acceptability and preliminary effectiveness

The primary objective was to assess the feasibility and acceptability of the EPHECT intervention as perceived by participating patients, family caregivers, general practitioners, oncologists and the palliative home care team. The feasibility and acceptability of the EPHECT intervention was evaluated in interviews with participating patients, family caregivers, GPs and oncologists who participated in the EPHECT intervention and in a focus group with the participating PHC team; and by registering the number of visits done by the PHC team, by analyzing the content of the conversations and the time spent on different topics, by registering and analyzing the amount of and reasons for interprofessional contact which was all gathered in the logbooks of the researcher, data nurse and the PHC team and in the electronic patient files.

The secondary objective was to assess the preliminary effectiveness of the EPHECT intervention on patient and family caregiver outcomes. The primary outcome was to assess the preliminary effectiveness of the EPHECT intervention on the patient's quality of life measured with the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30[66,67]), because previous interventions have proven a beneficial effect on quality of life. The secondary objectives were (1) to assess the preliminary effectiveness on the patient's mood, assessed with the Hospital Anxiety and Depression Scale (HADS[68,69]) and illness understanding, measured by a questionnaire developed by Temel et al. and translated by Vanbutsele et al., (2) to assess the preliminary effectiveness on informal caregivers' mood (HADS), satisfaction with care, assessed with the Family Satisfaction with End-of-Life Care (FAMCARE[70]) and illness understanding. The preliminary effectiveness of the EPHECT intervention was assessed with questionnaires comparing patient and caregiver outcomes at baseline and after 12, 18 and 24 weeks by the data nurse.

Dissertation outline

Following this introduction, chapter 2-6 of this dissertation are based on articles which have been published, accepted or submitted for publication.

This dissertation is further divided into two parts, consisting of different chapters that answer specific aims:

Part II of thesis focuses on the development phase of an intervention to support the early integration of palliative home care into oncology care. This part comprises the first aim of this dissertation and covers objectives 1 to 3 of this thesis.

In Part III we describe the feasibility, acceptability and preliminary effectiveness of the developed intervention and reflect on how to enrol advanced cancer patients into early palliative home care. This parts comprises the second aim of this thesis and covers objectives 4 to 7.

The final chapter of this dissertation (Part IV) consists of a summary of the main findings of this dissertation, reflections on strengths and limitations of the methodologies used, a discussion of the findings in the light of current palliative care research and a discussion of the implications of these findings for practice, policy and future research.

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PART II:

Development phase of an intervention to support the early integration of palliative home care into oncology care

Chapter 2:

Differences between early and late involvement of palliative home care in oncology care. A focus group study with palliative home care teams.

Abstract

Background: To date, no randomised controlled trials on the integration of specialised palliative home care into oncology care have been identified. Information on whether existing models of integrated care are applicable to the home care system and how working procedures and skills of the palliative care teams might require adaptation is missing.

Aim: To gain insight into differences between early and late involvement and the effect on existing working procedures and skills as perceived by palliative home care teams.

Design: qualitative study – focus groups interviews.

Setting/participants: Six palliative home care teams in Flanders, Belgium. Participants included physicians, nurses and psychologists.

Results: Differences were found concerning 1) reasons for initiation, 2) planning of care process, 3) focus on future goals versus problems, 4) opportunity to provide holistic care, 5) empowerment of patients, and 6) empowerment of professional caregivers. A shift from a medical approach to a more holistic approach is the most noticeable. Being involved earlier also results in a more structured follow-up and in empowering the patient to be part of the decision-making process. Early involvement creates the need for transmural collaboration, which leads to the teams taking on more supporting and coordinating tasks.

Discussion: Being involved earlier leads to different tasks and working procedures and to the need for transmural collaboration. Future research might focus on the development of an intervention model for the early integration of palliative home care into oncology care. To develop this model, components of existing models might need to be adapted or extended.

INTRODUCTION

Recently a number of studies have been conducted on the feasibility and efficacy of models of early integration of palliative care into oncology care. These studies, developed for palliative care in the hospital or outpatient setting, show a positive effect on the quality of life and on survival time.[1–5] In Belgium, as in many other countries, palliative care is not only provided in hospitals or outpatient clinics, but also at home[6] which allows patients to remain there with those close to them and to avoid unnecessary treatment in the hospital [7].

Palliative home care in Belgium is organised by 15 regional teams which support professional caregivers in the home context. They also support general practitioners (GPs) in their coordinating role by giving advice, doing home consultations and arranging multidisciplinary meetings[8]. The composition of the teams depends on the number of inhabitants in the region, but the minimum is two fulltime palliative care nurses, one palliative care physician (four hours a week) and one part-time administrative employee.[9]

Recent studies in Belgium have demonstrated that the median period of referral to palliative care for cancer patients is 15 to 20 days before death[10,11]. Statistics from the Belgian federation of palliative care show that only 20% of all interventions last more than 90 days[12] which indicates that the teams are most often involved late in an oncological trajectory but that they do have some experience with early integration of palliative home care.

No randomised controlled trials (RCTs) on the integration of specialised palliative home care in oncology care have yet been identified[13]. Existing models, in the hospital or outpatient setting, are based on common key components such as monthly visits and a systematic needs assessment[1–5], elements which might be useful in a model designed for palliative home care. Information on the key components necessary for the integration of palliative care in the home setting is lacking and these studies have not examined ways in which the procedures and skills of specialist palliative care teams require adaptation to becoming involved earlier in the disease trajectory.

Because of the growing interest in providing palliative care in the home setting, there is a need to develop a new model of early integration. Following the Medical Research Council (MRC) Framework for developing and evaluating complex interventions[14], gathering information on the subject and understanding the context is a crucial first step in the development of a complex intervention. Therefore, the aim of this study is to gain insight into differences between early and late involvement and the effect on existing working procedures and skills as perceived by palliative home care teams. The results will help us to develop an integration model applicable to the home care setting, in line with the current practice of palliative home care teams, in order to improve quality of life for people with advanced cancer.

METHOD

Design

In order to explore the individual experiences of professional caregivers we chose the most appropriate research design i.e. a qualitative one. We conducted six focus groups with palliative home care teams in Flanders, Belgium rather than using individual interviews; we considered that the multidisciplinary character of the teams would provide us with data from caregivers with varying backgrounds and job roles, thus seeing early palliative care themes from different perspectives[15] while stimulating reflection and discussion between professionals. This article follows the criteria for reporting qualitative research from the COREQ guidelines[16].

Participants

Participants were deliberately sampled by contacting the coordinators of all 15 palliative home care teams in Flanders via telephone. The most important reasons given for non-participation were: 1) the number of participants (too small to conduct a focus group) and 2) being overrun with research requests; six teams agreed to participate in one focus group each. After six meetings no new themes arose and the research team judged that data saturation had been reached and no additional groups were arranged.

Data collection

The focus groups were held between February 2016 and September 2016, either before or after the weekly multidisciplinary team meetings, guaranteeing a maximum of participants. All lasted approximately one hour and were moderated by ND and observed by junior or senior researchers making field notes.

A topic guide, consisting of open questions and a set of prompts for each question, was developed and reviewed within a multidisciplinary research team of sociologists (LD, ADV), psychologists (ND, KP) and a medical oncologist (SVB). This topic guide focused on following key topics: experiences with early integration of palliative home care, differences with late integration, barriers to early integration and discussion of a preliminary model based on existing models. This paper focuses on the first two topics.

Data analysis

All focus groups were audio-recorded, transcribed verbatim and analysed by a junior and a senior researcher (ND and ADV). Following an inductive approach, the constant comparative method was used to compare fragments within and between focus groups[17,18]. Firstly, the researchers independently read the transcripts and openly coded the data. Then a general conceptual interview scheme was composed with all the codes related to the research questions. This scheme was discussed in the multidisciplinary research team and codes were added or modified where necessary. Next, ND and ADV coded the transcripts using the final version of the conceptual codin4g scheme, from which overarching categories and themes were drawn. When no new information emerged data saturation was assumed. A final thematic framework was agreed and quotes from the focus groups were selected, translated and approved by the research team to illustrate the results. Qualitative data analysis software (NVivo 11) was used.

Ethical considerations

Ethical approval for this study was given by the Ethical Committee of Ghent University Hospital. We obtained written informed consent from all study participants.

RESULTS

Fifty-one professional caregivers (42 palliative nurses, seven palliative care physicians and two psychologists) attended one of the six focus groups. Characteristics of the participants per focus group are presented in Table 1.

Six themes emerged from the data: differences concerning 1) reasons for initiating palliative home care, 2) planning of care process, 3) different mind-set: focus on future goals versus problems, 4) opportunity to provide holistic care, 5) empowerment of patients, and 6) empowerment of professional caregivers in the home-care context.

Reasons for initiating palliative home care

When a palliative home care team is involved early in a disease trajectory, the focus is often on the introduction of the team and on giving general information about their working procedures. Psychosocial support is another common reason for early involvement according to participants of three focus groups, not only for the person who is dying but also for those close to them.

> *'Those are the patients with a request for psychosocial support or general information about the working procedures. Maybe not for intense contact or support, but just to know that we exist.' (FG1, R1)*

In contrast, late involvement of a palliative home care team is often triggered by a crisis situation when there is no more active oncological treatment available from the hospital. An acute request, mostly about end-of-life decisions or pain and symptom management, is a common reason for late involvement according to almost all participants.

Planning of care process

Systematic planning of the consultations

Early initiation of palliative home care can lead to a more systematic follow-up of the patient population as it makes it easier to plan visits systematically so that all patients get frequent face-to-face contact with the team.

> *'You can plan the visits whenever you want. Nothing is left to chance, you create a framework for everyone.' (FG5, R1)*

The visits may also be more structured, because the care trajectory is longer and there is more time to focus on a gradual build-up of the topics discussed, for example issues around end-of-life decisions might be discussed later in the care process when patients feel more comfortable with the palliative home care team. Visits can also be thoroughly prepared and follow-up matters raised earlier.

Telephone-based contact seems to be important for follow-up between face-to-face visits and can be a less time-consuming way of keeping in touch during periods of stability, which can be common when palliative home care is introduced at an earlier stage.

Needs-based planning of consultations

In a model of early integrated palliative home care, the care trajectory depends partially on the team planning it but also on the care needs of the person who is dying. A fluctuation in the intensity of follow-up is typical for a process of counselling that has started early in the disease trajectory, and this is strongly correlated with needs reported by the person or those close to them.

> *'You first have an introductory visit and then you evaluate the situation together with the patient and the family, to discuss the frequency of contact. When the situation deteriorates, the frequency of contact and the intensity of the support increase.'* (FG4, R7)

In nearly all focus groups participants reported the impression that a care process which started early in the trajectory had a more 'customised progression' than one that started in the terminal phase because there was more time to arrange the follow-up according to the wishes and the needs of the patient and family.

Different mind-set: focus on future goals versus problems

One focus group reported the impression that early involvement leads to a different mind-set in the team and a different approach to the patient and his or her disease trajectory allowing more space to focus on the positive things and on the activities and goals that can still be achieved, rather than focusing only on problems and on the impending death.

> *'When you say "we can't cure you but we will try to make the best of this situation", you are also focusing on living instead of just focusing on the impending death.' (F1, R1)*

Opportunity to provide holistic care

A longer care trajectory opens up some space to explore different problems and to make the focus broader than just pain and symptom management.

Psychosocial support

All focus groups confirm that earlier initiation leads to more opportunities to provide psychosocial support which is often the reason for being involved early in a disease trajectory.

Uncovering the underlying nature of the initial request

When a team is introduced early in the trajectory there may be more time to explore the initial request and to look for hidden problems and questions. The focus groups show that these usually arise only when a patient has already built up a relationship with the team, which might take longer than a couple of visits.

> *'The actual request often is merely just an indication of what's below the surface, patients typically have a lot more hidden problems or questions. So you have to unravel the initial request and this takes time.' (FG2, R3)*

Needs of the family caregiver

It was mentioned in almost all focus groups that a longer care trajectory also gives more space and time to take the needs and wishes of the family caregivers into account; however, one participant pointed out that it is important to keep the focus on the patient.

> *'Compared to the general practitioner, we typically not only have contact with the patient but also with relatives. Just like a travel agency, we can offer an all-inclusive treatment with a broader focus than just focusing on the patient and taking the family along in the trajectory.' (FG3, R4)*

Empowerment of patients

Acceptance of being a palliative patient

Nearly all focus groups showed that empowering the patient is one of the main purposes of earlier involvement e.g. allowing time for the process of acceptance.

Advance Care Planning (ACP)

Most participants feel that earlier involvement makes conversations about ACP more likely. Even though patients might live for years, that doesn't mean that they cannot have questions about 'what if'.

> *'I can imagine that someone diagnosed with breast cancer and with a prognosis of ten years, might have questions about what he or she must do when the condition deteriorates.' (FG3, R1)*

Empowering the patient in patient-caregiver communication

Participants also felt that empowering the patient in communicating their preferences about future care to other professionals is an important part of their role.

> *'Empowering the patients in taking steps. The same with end-of-life care. Have you already discussed this with your doctor and what did he say, do you have the feeling that he's taking initiative or that he's showing reluctance? We often have to help people in the communication to others.' (FG1, R1)*

Empowerment of professional caregivers involved in the home-care context

When palliative home care teams are involved late in a disease trajectory they may spend most of their time on hands-on care instead of the tasks defined in their job description.

Management and coordination of the care process

One of the main tasks of a palliative home care team is the coordination of the care process, bringing all disciplines together to communicate about which steps should be taken; in four focus groups participants felt that early involvement made this, rather than focusing on nursing tasks, more likely.

> *'In that way, being introduced much earlier, I think we will fulfil the role of palliative expert and coordinator instead of being a doer. We will be doers, but in terms of bringing people together and keeping people updated.' (FG1, R3)*

Fulfilling the role of palliative expert

It is the task of palliative home care teams to guide other professionals in providing palliative care; three teams thought that early involvement provides more time to support other professionals in their nursing tasks, to fulfil their own role as palliative care experts, to listen to the wishes of the patients and their families and to communicate these to other caregivers.

Three teams also report their experience that psychosocial support by palliative home care teams is not only given to patients and family but also to professionals involved in the home-care setting.

> *'In cases of people with complex needs, caregivers also like us to drop by because then they can let off some steam and don't have to carry everything by themselves. We often experience that, right, that they like us to come over, because for them on their own it also becomes emotionally and physically demanding.' (FG3, R6)*

DISCUSSION

Our study reveals that palliative home care teams experience important differences between early and late involvement of multidisciplinary palliative home care teams into oncology care. Six overarching themes were identified: differences concerning 1) reasons for initiating palliative home care, 2) planning of care process, 3) different mind-set: focus on future goals versus problems, 4) opportunity to provide holistic care, 5) empowerment of patients and 6) empowerment of professional caregivers involved in the home-care context.

According to our data, being involved earlier in an oncological disease trajectory leads to a number of different tasks and working procedures for a palliative home care team compared with late involvement.

In terms of the content of care given by a palliative home care team, a shift from a medical approach focusing on pain and symptom management to a more holistic approach is the most noticeable difference. Palliative care, as defined by the WHO, is a holistic approach which focuses on not only pain and physical aspects but also on psychosocial and existential aspects[19]. While this is widely accepted, our data show that it does not always happen with late involvement but can be implemented to the fullest when palliative care is introduced earlier. Furthermore, the Clinical Practice Guidelines for Quality Palliative Care, which some previous intervention studies have used to determine the key components of the intervention model, state that qualitative palliative care should consist of a combination of physical and psychosocial care[20]; other existing models of integration also stress the importance of psychosocial care. Early home visits make a gradual build-up in conversation topics possible. One of the first RCTs shown to be effective on the early integration of palliative care into oncology care is the intervention of Temel and colleagues, developed in the hospital setting. In this intervention, the palliative care team visited the patients in the intervention arm at least monthly.[1] Yoong et al. have analysed data of the visits done by the palliative care team to identify key elements of early palliative care visits and to explore the timing of key elements and found that the main focus of initial visits in early intervention lies in relationship- and rapport-building while conversations about the end of life and discussions about future care are more prominent later in the care process.[21]

Important differences between early and late involvement have also been found when looking at aspects of the caregiving trajectory. Where late involvement is often correlated with crisis situations and the follow-up is based on pain and symptom management, early involvement implies a follow-up structured by a combination of the team's agenda and the needs and wishes of the person who is dying and those close to them. Previous intervention studies have defined monthly visits by a palliative care team as a key component[1–5]; however, our data show that the involvement of patients and family caregivers in discussing the structure of care and the number of visits is recommended. Also, communication can be augmented by telephone contact between visits. Being involved early also implies more home visits which probably leads to an increase in workload. Given the fact that the teams already feel that they are understaffed, an expansion of resources might be necessary[22].

Our data show that early involvement leads to opportunities to provide holistic care, in line with previous existing models and with the definition of palliative care given by the WHO[1–5,19]. A recent Delphi survey on indicators of integration of oncology and palliative care programmes underlines the importance of education for professional caregivers in the process of integrated care[23]. Furthermore, according to our participants and to previous research, a systematic structure can be seen in topics discussed during the home visits[21,24]. As a consequence, a structured overview of key topics and recommendations on when they should be introduced can be a helpful tool for earlier involvement. Other research also suggests the value of a conversation guide in communicating about serious illnesses[25].

Our results show that early involvement leads to the palliative home care teams taking on more coordinating tasks like bringing all disciplines together to discuss which steps should be taken next. As a result, the need for transmural collaboration arises, which is an important difference with existing interventions in the hospital setting. Because in this model palliative home care and oncology care will be provided simultaneously, regular contact between the home setting and the hospital setting is crucial. Therefore, one of the key components in making this happen will be the structuring of this transmural communication and the provision of support for the palliative home care teams in their role as co-coordinators of the care process, together with the GP. It might be necessary to evaluate the latest developments in communication methods to find a shared communication platform applicable to all disciplines. Related to this, and also in order to guarantee continuity of care, the support of the palliative home care teams is needed to empower patients in their communication with other professionals. To fulfil these tasks in a system of concurrent provision of palliative and oncology care, education in oncological diseases and treatments will be an important component of the intervention.

Because early involvement leads to different working procedures and different tasks, the structure and composition of a palliative home care team might have to be reconsidered. For example, one of the main tasks of early palliative care is the provision of psychosocial care; palliative care nurses or physicians may not be able to handle some of the psychosocial problems that arise so it might be useful to add a psychologist to the team.

Strengths and limitations of the study

To our knowledge, this study is the first qualitative study to explore the experiences of palliative home care teams with early integration into oncology care and what they perceive as the differences between early and late involvement. The multidisciplinary character of the teams allowed us to gain insight into this from different perspectives (physicians, nurses and psychologists) and from different points of view. An advantage of the use of pre-existing teams is that the members are used to working together and to discussing openly their working procedures, their patients and the topics which stimulate self-reflection[15,26]. A limitation of our study is that the data depended on the subjective experiences and responses of the respondents, responses that might have been affected by social desirability.

Conclusion and implications for future research

Being involved earlier rather than later in an oncological disease trajectory leads to a number of different tasks and working procedures for a palliative home care team. Because palliative care is organised differently in different countries, future research is needed on whether these differences are also noticeable in other settings and what effect they have on working procedures and tasks. Perceptions about differences between early and late involvement of palliative home care from other professional caregivers (e.g. oncologists and general practitioners) and patients and relatives might provide more insight into what leads to optimal palliative care; this also requires future research. Further research might focus on the development of an intervention model for the early integration of palliative home care into oncology care. To develop this integration model, key components of existing models can be used but adaptations or extensions might be necessary.

Figure 1: Topic guide of the focus groups with palliative home care teams

Introduction

Theme 1: experiences with early integration

1. According to you, what is meant with early integration?
2. In which way differ early trajectories from late trajectories?
3. How is the collaboration with other professional caregivers organized?
4. What are the reasons for late involvement?

Theme 2: reflections on intervention model

1. Is this model applicable to your healthcare system?
2. Which components should be kept, deleted, or adjusted?
3. Do you have alternatives for those components?

Table 1: Characteristics of participating palliative home care teams (N=6)

	Number of participants						
Characteristics	Focus group 1	FG2	FG3	FG4	FG5	FG6	Total
Total N	8	8	7	10	10	8	51
Sex							
Male	4	3	3	3	1	2	16
Female	4	5	4	7	9	6	35
Age							
≤29		3		1		2	6
30-39	1	1	2	3		3	10
40-49	2	3	1		4	2	12
50-59	3		4	3	3	1	14
60-69	3	1		3	2		9
Discipline							
palliative care physician	1	1		2	2	1	7
palliative care nurse	7	7	6	7	8	7	42
palliative care psychologist			1	1			2
Years of working experience							
≤5		3	2	2	3	1	11
6-9	1			1	2	2	6
10-14	3	2	2	2			9
14-19		2	2	1	2	2	9
≥20	4	1	1	4	3	3	16
Years of experience of palliative home care							
≤5	2	6	5	3	5	3	24
6-9	2	2		2	2	3	11
≥10	4		2	5	3	2	16
Estimated number of patients with oncological diagnoses in last year by the team	450	400	250	805	350	625	2880

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Chapter 3:

Barriers to the early integration of palliative home care into the disease trajectory of advanced cancer patients. A focus group study with palliative home care teams.

Abstract

Objectives: Palliative care is still often involved late in the disease trajectory. Recently, some studies have explored the barriers to early integration of PC in the hospital setting. Because palliative care home care (PHC) is organised differently compared with PC in a hospital setting, the identification of barriers to the early integration of PHC is needed.

Methods: Six focus groups were held with PHC teams in Flanders, Belgium. Discussions were transcribed verbatim and analysed using constant comparative analysis.

Results: Our findings confirm many barriers found in previous studies, such as the lack of financial resources and the perception of PC as terminal care. Oncologists' lack of knowledge about the content and role of PC is also confirmed. Furthermore, professional caregivers working in the home context are lacking information on oncology therapies necessary to provide optimal PC. A barrier for the home context is the discontinuity of care, as a result of a lack of communicational structure and a lack of central coordination.

Conclusion: The results contribute to a better understanding of the factors hindering the provision of PHC alongside oncology care. For the home context, transmural discontinuity of care seems to be an important additional barrier.

INTRODUCTION

Recent studies have shown that the early provision of specialist palliative care (PC) concurrent with active oncology care has beneficial effects on the quality of life and mood of the patient and the family caregiver(Bakitas et al. 2009; Bakitas et al. 2018; Temel et al. 2013; Maltoni et al. 2016; Zimmermann et al. 2014); and even on survival[2,3].

As defined by the WHO definition and as recommended by the ASCO in the US and by the MASCC, ESMO and EAPC in Europe, we in Belgium also subscribe to a model of concurrent care (palliative care during and after disease-modifying therapy) of early palliative care.[7–10] Palliative patients in Belgium are defined as patients suffering from an incurable, progressive, life-threatening disease, with no possibility to obtain remission or stabilization or restraining of the illness, while although part of palliative care, terminal care in Belgium is considered as care for patients with a life expectancy of less than 3 months.[11]

Recently, Vanbutsele et al. (2018) developed the first Belgian study on this palliative patient population also showing positive effects of early integration of specialist PC in oncology in the hospital setting.[6] However, in Belgium the use of specialist PC services in the outpatient setting increases because the majority of palliative patients prefer to spend the last months of their life at home.[12] Professional caregivers working in palliative home care (PHC) teams have a much broader view of the wider supportive context of the patient. Also, PHC teams provide support and advice to the general practitioner (GP) and can make the bridge between healthcare professionals in the hospital and in the home setting[11]. Although the use of extramural services increases, data from 2014 show that 60% of all care trajectories of the PHC teams in Belgium last less than 30 days, only 18% last longer than 90 days and only 9% longer than 180 days[13].

Recently some international research has been conducted on barriers to early integration of palliative care into oncology care in a hospital setting, as perceived by oncologists and organ specialists. The most important barriers found were 1) the lack of knowledge of oncologists about the content of PC and what PC has to offer, 2) the existing societal perception of PC as terminal care resulting in resistance to involving it early from patients, caregivers and physicians in order to maintain hope, 3) the lack of available financial resources for the integration of PC into oncology care.[14–17] However, no studies have looked into barriers to the early integration of PHC into oncology care.

PHC teams have valuable information about how PC is structured and organised in the home setting and about how they work together with oncological services. Therefore, the aim of this study is to explore the existing barriers to early integration as perceived by the PHC teams.

METHOD

Design

In order to explore the individual experiences of professional caregivers we chose the most appropriate research design i.e. a qualitative one. We conducted six focus groups with PHC teams in Flanders, Belgium rather than using individual interviews; we considered that the multidisciplinary character of the teams would provide us with data from caregivers with varying backgrounds and job roles, thus seeing the themes from different perspectives while stimulating reflection and discussion between professionals[18]. This article follows the criteria for reporting qualitative research from the COREQ guidelines[19].

Participants

Participants were purposively sampled by contacting the coordinators of all 15 PHC teams in Flanders. Some teams refused to participate and most frequent reasons for decline were: 1) the number of participants (too small to conduct a focus group) and 2) being overrun with research requests; six teams agreed to participate in one focus group each. After focus groups with six teams no new information arose and the research team judged after analysing the field notes that data saturation had been reached and no additional focus groups were arranged.

Data collection

The focus groups were held between February and September 2016, either before or after the weekly multidisciplinary team meetings, guaranteeing a maximum of participants. All lasted approximately one hour and were all moderated by ND, supported by different junior and senior researchers.

A topic guide (Figure 1), consisting of open questions and a set of prompts for each question, was developed and reviewed within a multidisciplinary research team of sociologists (LD, ADV), psychologists (ND, KP), and a medical oncologist (SVB). The topic guide focused on different aspects of PC for advanced cancer patients: experiences of early integration of PHC – i.e. PC during and after disease-modifying therapy –, differences with late integration of PHC, barriers to the early integration of PHC, and discussing a preliminary model based on existing models. This article focuses on the barriers found to the early integration of PHC into oncology care.

Figure 1: Topic guide of the focus groups with palliative home care teams

Introduction

Theme 1: experiences with early integration

5. According to you, what is meant with early integration?
6. In which way differ early trajectories from late trajectories?
7. How is the collaboration with other professional caregivers organized?
8. What are the reasons for late involvement?

Theme 2: reflections on intervention model

4. Is this model applicable to your healthcare system?
5. Which components should be kept, deleted, or adjusted?
6. Do you have alternatives for those components?

Data analysis

All focus groups were audio-recorded, transcribed verbatim and analysed by two researchers (ND and ADV). This paper focuses specifically on the perceived barriers to the early integration of PHC. Following an inductive approach, the constant comparative method was used to compare fragments within and between focus groups[20,21]. Firstly, the researchers independently read all the transcripts and openly coded all the data. Then a general conceptual interview scheme was composed with all the codes related to the research questions. This scheme was discussed in the multidisciplinary research team and codes were added or modified where necessary. Next, ND and ADV coded the transcripts using the final version of the coding scheme, from which overarching categories and themes were drawn. Analyses started after the first interview and during the process of data collection. We started with a code tree and refined it based on the input of the research team. Thematic saturation was determined by consensus when no new themes in relation to the research questions emerged in the last FG. A final thematic framework was agreed and quotes from the focus groups were selected, translated and approved by the research team to illustrate the results. Qualitative data analysis software (NVivo 11) was used.

Ethical considerations

Ethical approval for this study was given by the Ethical Committee of Ghent University Hospital. We obtained written informed consent from all study participants.

RESULTS

Fifty-one professional caregivers (42 palliative nurses, seven palliative care physicians and two psychologists) attended one of the six focus groups. Characteristics of the participants per focus group are presented in Table 1.

Table 1: Characteristics of participating PHC teams (N=6)

	Number of participants						
Characteristics	FG 1	FG2	FG3	FG4	FG5	FG6	Total
Total N	8	8	7	10	10	8	51
Sex							
Male	4	3	3	3	1	2	16
Female	4	5	4	7	9	6	35
Age							
≤29		3		1		2	6
30-39	1	1	2	3		3	10
40-49	2	3	1		4	2	12
50-59	3		4	3	3	1	14
60-69	3	1		3	2		9
Discipline							
PC physician	1	1		2	2	1	7
PC nurse	7	7	6	7	8	7	42
PC psychologist			1	1			2
Years of working experience							
≤5		3	2	2	3	1	11
6-9	1			1	2	2	6
10-14	3	2	2	2			9
14-19		2	2	1	2	2	9
≥20	4	1	1	4	3	3	16
Years of experience of PHC							
≤5	2	6	5	3	5	3	24
6-9	2	2		2	2	3	11
≥10	4		2	5	3	2	16
Estimated number of patients with oncological diagnoses in last year by the team	450	400	250	805	350	625	2880

According to the participants, there are many barriers to the early involvement of PHC into oncology care. An overview is given in Table 2.

A. Societal perception of PC as terminal care

An overall barrier that influences patients, family members and professional caregivers is the existing societal perception that PC is only initiated when death is close. As mentioned in two focus groups, oncological diseases have now become more treatable and patients can be palliative over many years, which weakens the link between being palliative and being terminally ill. But some participants mentioned there is still confusion between the terms ‘palliative care’ and ‘terminal care’ which might lead to late involvement of PHC teams in a disease trajectory.

> *“Sometimes people still see us as the grim reaper, we still bring the death inside the house.” (FG1, R5)*

B. Patients’ knowledge and attitudes

1) Lack of accurate information about diagnosis or prognosis

Whether PHC can be involved earlier in the disease trajectory depends on the extent to which patients have received accurate information about their diagnosis and prognosis according to the participants of one focus group who expressed the view that too many patients are still not getting the right information about their disease, sometimes not knowing that they have an incurable disease thus making it hard to introduce PC and to initiate PHC early in their trajectory.

2) Readiness to accept being a palliative patient

In one focus group, participants stressed the importance of being aware of the patient’s possible denial about being palliative and about suffering from an incurable disease, although they may realise they have a terminal condition. A patient can be diagnosed as being palliative based on medical criteria, but that does not automatically lead to their acceptance of the status and might lead to resistance to the support of a PHC team.

> *“What if the patient does not want to be palliative?” (FG4, R5)*

> *“Then that patient doesn’t have palliative needs.” (FG4, R7)*

3) Willingness to receive PC

The possible reluctance of patients or their families to having a PHC team – related perhaps to the societal perception of PC – was mentioned in almost all focus groups as an important barrier; does the person who is dying or those close to them want the support of a PHC team?

C. Professional caregivers’ knowledge

1) PHC teams’ knowledge of oncology

According to some participants of two focus groups, palliative caregivers are not informed enough about oncological diseases and newly developing chemotherapies to help advanced cancer patients in understanding their disease and treatment.

2) *Oncologists' knowledge of PC and how to refer to PC*

Almost all participants had the feeling that even though the curriculum in Medical School is continuously changing, there still needs to be more space given to PC and students need better training in delivering bad news to patients and those close to them if there is to be more PC provided. A lack of knowledge about PC and how to refer to it could lead to resistance to introducing it and to the fear of depriving the patient of hope.

D. Lack of conceptual clarity of a PHC team

1) *Discrepancy between practice and policy*

Given the societal perception of PC as terminal care and the lack of knowledge of PC among other healthcare professionals, PHC needs to be more clearly defined so the teams find it easier to explain their tasks and working procedures to others; oncologists and other professional caregivers clearly lack crucial information and understanding about the content of PHC and the role a PHC team can play in the care of a patient when involved early in the disease trajectory.

One possible result of this lack of conceptual clarity is that other professional caregivers do not know PC is more than controlling symptoms in crisis situations, like helping patients to accept life and to see dying as a normal process. One team had experiences with GPs who contacted them with an acute request and then resisted the suggestion of a 'full' care trajectory.

2) *Lack of uniformity among teams*

Related to this, one important barrier is the lack of uniformity between the 15 palliative networks in Flanders, Belgium. Most participants have the impression that working procedures of the 15 teams differ and this might be a barrier to building up a systematic way of integrating PC into care. Each team is working in a specific region and some hospitals – especially university hospitals – have patients from different regions in Flanders. A lack of uniformity between the teams and their working procedures could make it difficult for these hospitals to involve them.

> *"There is still work to do. We have to know the working procedures of the other teams and we have to bring uniformity and structure, so that patients in different regions receive the same information." (FG1, R7)*

E. Barriers related to transmural discontinuity of care

Because of the ongoing oncological treatment that in almost all cases takes place in the hospital setting and the additional support by the PHC team, early involvement of PHC in oncology care leads to an unavoidable need for collaboration between professional caregivers in both the hospital and the home setting. According to the participants, important barriers to the integration of PHC into oncology care arise from a lack of transmural continuity of care.

1) *Lack of communicational structure*

It is not always clear with whom they have to communicate, when they have to communicate and how they have to communicate. According to the participants, there is still a problematic hierarchical structure between professional caregivers, and also between different settings. Palliative nurses of the PHC teams rarely communicate directly with the oncologist because they feel they do not have a mandate to contact them. Furthermore, because so many different professional caregivers can be involved in the hospital, it is not always clear who they should contact, which can lead to discontinuity in the transfer of information.

Participants have thought about how inter-professional communication should work. In general, they mentioned that the existing differences in electronic medical records among settings and regions and thus the lack of a shared communication tool is one of the biggest barriers to the transmural integration. Related to this, they also have concerns about communication tools. Although a shared digital platform might be a user friendly and timesaving tool, in all focus groups the importance of telephone-based contact and also face-to-face contact due to the relevance of non-verbal and contextual information was stressed. Despite the relevance of face-to-face contact, practical and financial issues are important barriers to having such contact on a regular basis which has a negative impact on the integration process.

> *"Not everything can be written, and then you have to open up the dialogue with the physician." (FG6, R9)*

The participants have not only thought about how to communicate, but also about when communication should take place in the disease trajectory. When a patient is transferred between settings clear communication is necessary. However, not only at these moments but during the whole care process optimal communication between settings is needed and at present a lot of this is missing. Some teams also stressed that more contact is required between professional caregivers in the home setting; participants have the feeling GPs should give more feedback after a consultation and also PHC teams could communicate more to other professional caregivers after a home visit.

2) *Lack of a central coordinator*

A crucial professional caregiver in the care for a patient in Belgium is the GP: he or she is the one that often knows the most about the patient and his or her social context. Most participants agree that the GP needs to be the key person in a care trajectory. According to almost all participants an important barrier here is that GPs are often out of the picture during oncology treatment which might cause discontinuity of care between the home setting and the hospital setting.

> *"The GP is the captain of the ship, the key person in the care for a patient. Unfortunately, at this moment he can't fulfil this role." (FG2, R1)*

F. Future concern : lack of financial resources

Available resources are not enough to cover systematic early involvement of PHC. In all focus groups, the concern arose that a lack of financial resources will become an important barrier to systematic early integration as patients will be referred and care trajectories will last longer if initiated earlier.

Table 2: Barriers according to PHC teams to involve PHC early in oncology care

Existing societal perception of palliative care as terminal care
Knowledge and attitudes of patients Lack of valid information about diagnosis and/or prognosis Readiness to be a palliative patient Willingness to receive palliative care
Knowledge of professional caregivers Lack of knowledge about oncological diseases and treatments (PHC/GP) Lack of knowledge about palliative care (oncologist/GP)
Lack of conceptual clarity about palliative home care Lack of a clear definition of palliative home care Lack of uniformity among the working procedures in the teams
Transmural discontinuity of care Lack of a communicational structure Lack of a central coordinator
Future concern: lack of available financial resources

DISCUSSION AND CONCLUSION

Principal findings

The findings of this qualitative study confirm results found in previous studies, such as the concern that there will be a lack of available financial resources to ensure the provision of optimal integrated PC and the existing societal perception of PC as terminal care resulting in possible negative attitudes to early involvement of PC. Furthermore, the perception of PC teams that oncologists lack knowledge about the content of PC and what it can offer is confirmed in this study. Our study also reveals that professional caregivers working in the home context, such as GPs and PHC teams, are lacking the information about the oncological treatment they need to provide optimal PC. An important additional barrier specific to this setting in such a transmural model of integration is the discontinuity of care between the hospital and the home setting, as a result of a lack of communicational structure and a lack of central coordination of the care trajectory.

Strengths and limitations

To our knowledge, this is the first study exploring the experiences of PHC teams of perceived barriers to the early integration of PHC into oncology care. The multidisciplinary character of the teams allowed us to gain insight into this topic from different perspectives (physicians, nurses and psychologists) and from different points of view. An advantage of the use of pre-existing teams is that the members are used to working together and to discussing openly their working procedures, their patients and the topics which stimulate self-reflection[18,22]. A first limitation of this study is that the results might not necessarily be generalisable to other countries or other healthcare systems. Although we expect our findings to be applicable to PHC teams in several countries, experiences and perceptions of early palliative care in Belgium may be different from those in other countries, especially those with dissimilar primary or secondary care systems. Secondly, a possible risk might be that responses might have been affected by social desirability, but we estimate this effect is rather small due to the similar results found in the different focus groups. Also, the perspective of the PHC teams is essential in obtaining information about PC given in the home setting. However, other perspectives such as those of patients and relatives and also of other professional caregivers like GPs and oncologists could provide additional insights into the barriers to the early integration of PHC.

Comparison with existing literature

Most of the barriers found in this focus group study are confirmed by several previous studies executed in different countries such as England, Germany, Norway, Australia, the US and Canada. For example, a lack of financial resources is defined in several studies as a major concern[14,17,23,24], as well as the fragmented structure of the health care society resulting in difficulties in the communication between professional caregivers[15,17,25].

In all focus groups participants reported the societal perception of PC as terminal care as a major barrier. Despite these recommendations and despite positive results of previous interventions, both clinical practice and society still do not acknowledge the relevance and advantages of early PC. Even though oncological diseases are becoming more and more treatable and there are demonstrable advantages to receiving PC from diagnosis, the stigma around 'palliative care' still exists. Also, as found in the literature, physicians still have concerns about loss of hope and fear of negative patient reaction when introducing PC early.[14,15,25–29] Other studies have revealed that oncologists are more likely to refer palliative patients to services called 'supportive care' than 'palliative care'[30,31].

However, this commonly cited barrier might possibly be overcome through education. A key element in education for clinicians is to provide a clear understanding of the content of PC. Education about PC should specify what PC can offer early in a disease trajectory, focusing on the holistic approach as defined by the WHO instead of on pain and symptom management.

Previous research also shows that students in medical schools and professional caregivers in clinical practice have little training in PC and that they are not always confident in situations that require PC consultation or referral[14,16,17,29,32].

An important additional barrier specific to this transmural model of integration is the discontinuity of care between the hospital and the home setting. GPs are seen as central coordinators of care but according to several participants, they are often not involved during active oncological treatment or they lack the time to fulfil this role. A recent study focusing on healthcare professionals' attitudes towards collaboration in PHC in Flanders shows that GPs do see the coordination of care as part of their job, but they admit that this is a demanding and time-consuming task[32]. The central role of GPs might be facilitated by better structuring the interdisciplinary and transmural collaboration. The discontinuity of care is mostly due to a lack of a transmural communicational mechanism; there is a need for the lines of responsibility and tasks of all professional caregivers to be clearly defined. Furthermore, guidelines on when transmural communication should take place in the disease trajectory are needed, as well as on how it should be organised. A lack of clear task descriptions of specialised PC teams and not knowing whom to address for certain problems are seen as important barriers to interdisciplinary collaboration[15,29,32] and are confirmed in this qualitative study. We might have to think about creating a shared web-based communication platform to support the continuity of care. However, because information might be lost when communicating only through written communication tools, and to reduce uncertainty about task descriptions and how settings can work together, multidisciplinary transmural meetings might be a necessary addition to that platform. Since 2003 multidisciplinary oncology consults (MOCs) are part of the oncological treatment, but a recent evaluation report shows that these consults won't work in a model of early integrated palliative care. GPs are rarely present on the meetings and a patient is discussed for less than 10 minutes, mostly focusing on medical data and treatment options leaving no space or time for palliative care issues.[33] We might have to think about developing a new format for multidisciplinary meetings on palliative care patients, involving oncologists, GPs, patients and family carers. These meetings and positive experiences with each other might facilitate future referrals to PC and future collaboration because by spending time together in a respectful way they learn to appreciate the work each one does and to have trust.

Conclusion and implications for practice, policy and research

Our data confirm many barriers to the early integration of PC into oncology care found in previous studies, and in the context of the home setting, a lack of transmural collaboration and interdisciplinary communication seems to form a major extra barrier.

We have to be aware of the existing barriers and have to think about appropriate actions to overcome them by developing an intervention to support the early integration of PHC into oncology care. Education for patients and clinicians is needed, specifically on the components of PC and what PC has to offer early in a disease trajectory. Internships in PC settings would provide experience with PC and end-of-life care. Professional caregivers also need more training in having bad news conversations and in communicating to patients about diagnoses and prognoses, because patients often miss important information which prevents them from having informed discussions about their preferences for future care, as is found in our study and in previous research. Lastly, professional caregivers working in the home setting need more information about oncological diseases and treatments to provide optimal PC concurrent with oncology care.

Furthermore, interdisciplinary communication need to be structured and both settings need to be trained in working together to reduce the uncertainty about task descriptions and responsibilities. Lastly, we have to think about how to take into consideration the individual wishes and needs of the person who is dying and those close to them when developing an intervention because PC is only possible when patients and relatives accept its involvement.

Although complex interventions consisting of multiple components can tackle different barriers, for some barriers, policy recommendations are needed. Policy makers need to be aware of the existing societal perception of PC as terminal care. Therefore, public campaigns might be necessary and more research has to be done on whether PC might have to be renamed as supportive care, and what the effect will be on the attitudes of professional caregivers and patients. Furthermore, expansion of financial resources might be necessary when PHC is involved systematically earlier in a disease trajectory, which possibly will lead to longer care trajectories and to more patients being referred to PHC teams.

The focus of this study was to gain insight into the perspectives of PHC teams on the existing barriers to the early integration of PHC into oncology care, but future research is needed on other perspectives such as that of the person who is dying and those close to them. Future research should also focus on existing barriers for the early integration of palliative care in the trajectory of patients with other chronic diseases. The next step will be to use these insights for the development and testing of an intervention to overcome the barriers found in this study.

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Chapter 4

Development of a Phase 0-1 early palliative home care cancer treatment intervention study (the EPHECT intervention).

Abstract

Objectives: Recent studies have shown that the early provision of palliative care (PC) integrated into oncology in the hospital has beneficial effects on the quality of life of people who are dying and their family caregivers. However, a model to integrate palliative home care (PHC) early in oncology care is lacking. Therefore, our aim is to develop the Early Palliative Home care Embedded in Cancer Treatment (EPHECT) intervention.

Methods: We conducted a Phase 0-1 study according to the Medical Research Council (MRC) Framework. Phase 0 consisted of a literature search on existing models for early integrated PC, and focus groups with PHC teams to investigate experiences with being introduced earlier. In Phase 1, we developed a complex intervention to support the early integration of PHC in oncology care, based on the results of Phase 0. The intervention components were reviewed and refined by professional caregivers and stakeholders.

Results: Phase 0 resulted in components underpinning existing interventions. Based on this information, we developed an intervention in Phase 1 consisting of: 1) information sessions for involved professionals, 2) GP as coordinator of care, 3) regular and tailored home consultations by the PHC team, 4) a semi-structured conversation guide to facilitate consultations, and 5) inter-professional and transmural collaboration.

Conclusion: Taking into account the experiences of the PHC teams with being involved earlier and the components underpinning successful interventions, the EPHECT intervention for the home setting was developed. The feasibility and acceptability of the intervention will be tested in a phase II study.

INTRODUCTION

People with advanced incurable cancer typically suffer from a multitude of severe symptoms such as pain and dyspnea that often appear undertreated; they also experience psychological symptoms such as depression and anxiety.[1,2] Palliative care can mitigate these problems, but is usually only provided late in the course of the disease when death is imminent.[3–5] Recent studies have shown that the early provision of palliative care integrated into oncological treatment in the hospital setting has beneficial effects on the quality of life of people who are dying and those close to them.[6–10]

However, palliative care is not only provided in hospitals or via outpatient clinics but also at home. This allows people to stay at home, supported and surrounded by those close to them, which helps to avoid unnecessary treatment in a highly technological hospital setting.[11] A recent systematic literature review shows that the majority of cancer patients prefer to be cared for and die in their own homes.[12] In Belgium, palliative home care (PHC) teams consisting mostly of palliative care nurses, accompanied by one or two palliative care physicians and a psychologist, provide specialised palliative care in the home setting and give support to both patients and those caring for them and provide specialist advice to general practitioners (GPs) and nurses. PHC teams have an advisory and mentoring function for primary care provision at home, and expertise in pain therapy, symptom control, and psychosocial support.[13] However, despite the possible advantages of early PHC for patients with advanced cancer, an evidence-based model for the provision of palliative home care concurrent with oncology care has been lacking[14].

Our previous study based on focus groups done with PHC teams in Belgium shows that nurses of the specialized palliative home care team have the feeling that they can focus on more components of palliative care than only symptom management when being involved earlier. This creates more time to focus on coordination of care, bridging the gap between hospital and home settings, providing holistic care and giving expert advice to primary caregivers.[15–19] However, the results of this study also show that integrating palliative home care into standard oncological treatment at home is more complex than doing it in the hospital or outpatient clinics[20]. Inter-professional and transmural collaboration – ie. collaboration between healthcare professionals working in different settings – is pivotal, as is cooperation with general practitioners (in Belgium the GP must give approval to start palliative home care[21]).

This phase 0-1 trial study aims to develop and evaluate the EPHECT intervention to initiate and improve the early integration of palliative home care in standard oncology care in the health care system of Flanders, Belgium.

METHOD

Study design

The intervention development followed the guidance of the Medical Research Council (MRC) framework for development and evaluation of complex interventions.[17] The study entails the development and modelling (phase 0 and I) of a complex intervention to facilitate the early integration of palliative home care into standard oncological treatment of people with advanced cancer.[22,23] An overview of the phases and methods used for the development of the EPHECT intervention following the MRC framework can be found in Table 1.

Phase 0: identifying evidence based practices

The key components of an intervention refer to the essential features that define an effective intervention and produce desired outcomes[24]. Two complimentary methods were used to identify the key components of this intervention.

1. Literature search

We performed a screening of the literature of existing and tested models of integration of palliative care into oncological care in different care settings and different countries. We limited our search to randomised controlled trials on integrated oncology care for people with advanced cancer and a prognosis of two years or less. The RCTs needed to have an explicit early palliative care intent, i.e. concurrent with oncology care, with advanced cancer patients as patient population, and needed to be interdisciplinarily orientated following the WHO definition of early palliative care[25]. We only included trials showing a positive effect on primary or secondary outcomes. We searched on PubMed and limited our search to studies that were published before the end of 2016, because the analyses of the literature search and the building of the intervention model started in 2017.

2. Focus groups with PHC teams

We conducted six focus groups with members of the PHC teams (n=51) to gain insight into differences between early and late involvement of PHC and into perceived barriers to early involvement. We also discussed a preliminary model for early integration based on the key components identified in the literature with the aim of reflecting on them and adapting them to the current working context of PHC in Flanders. As those teams have a coordinating role in organising primary healthcare, they are ideally placed to provide contextual insights and essential information on how palliative care is structured and organised in the home setting and on how they work together with oncological services.

Participants were deliberately sampled by contacting the coordinators of all 15 PHC teams in Flanders. Some teams refused to participate and most frequent reasons for decline were: 1) the number of participants (too small to conduct a focus group) and 2) being overrun with research requests; six teams agreed to participate in one focus group each.

Phase 1: modelling of EPHECT intervention and development of the intervention materials

Based on the results of phase 0, we developed a preliminary intervention model to support the early integration of palliative home care into oncology care. During the modelling phase, we conducted semi-structured interviews with members of a PHC team and oncologists and used their feedback on the preliminary model. We also held 4 stakeholder workshops with representing patient groups, family carers, professionals working in palliative and primary care and with policy makers. The aim of this participatory approach was to explore the experiences of people with a serious illness and those surrounding them, and to brainstorm about how to further improve the intervention model.[26] The model was further refined at monthly meetings with the multidisciplinary research team consisting of psychologists, sociologists and a medical oncologist.

RESULTS

Phase 0: identifying core components of the intervention

Identifying the evidence base

The screening of the literature resulted in five studies (Figure 1) of which three were executed in the United States[6–8], one in Canada[10], and one in Italy[9] (Table 2). Two of the interventions for early integration of palliative care were developed for the hospital setting[8,10], and three for outpatient clinics[6,9,27]. None was specifically developed for specialised palliative care provided by a PHC team. Inclusion criteria differed across the interventions. Some studies used specific cancer diagnoses like non-small cell lung cancer[8] or pancreatic cancer[9], others included different cancer diagnoses[6,7,10]. Studies also differed on the expected survival time, with variations between two months[9] and two years[10,27].

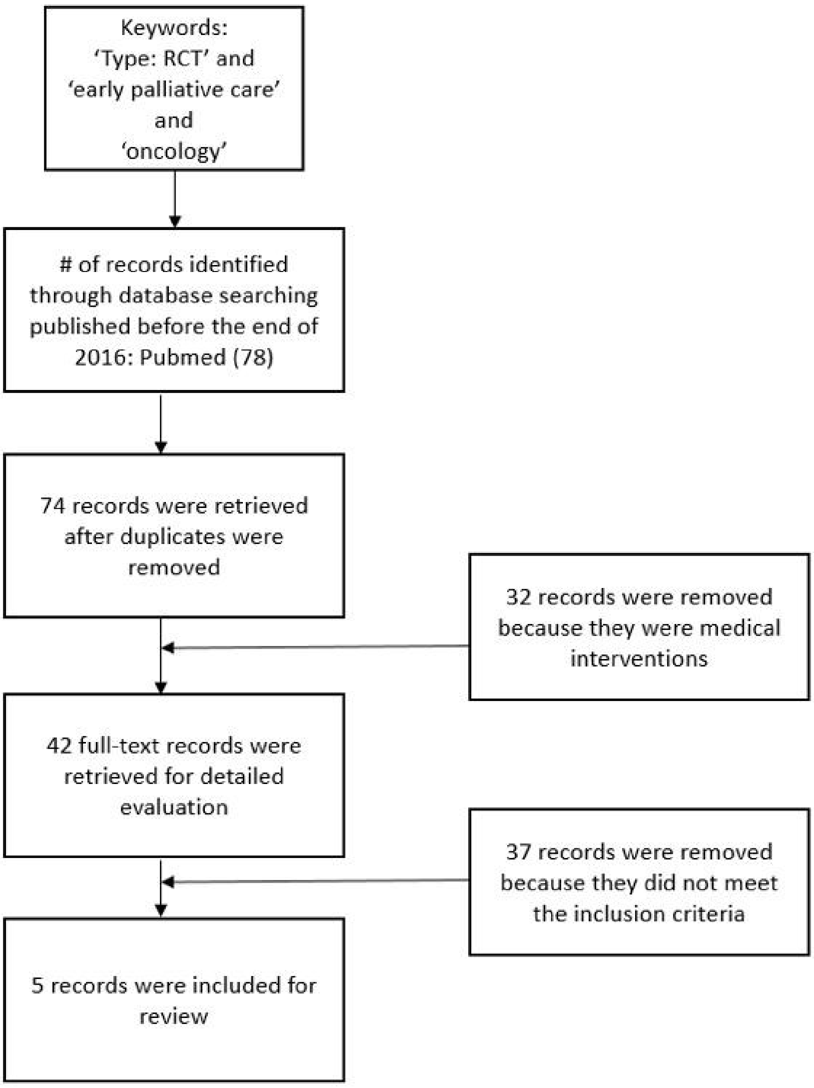


Figure 1: full electronic search strategy

Based on the screening of these five studies, we identified the following three key intervention components:

1) Regular consultations by a member of the palliative care team

In all interventions, a member - mostly a nurse - of the palliative care team from the hospital or outpatient clinic visited the patient regularly.[6–10] The frequency of the visits or contacts ranged from weekly to at least monthly. Most interventions used in-person contacts with telephone-based contacts for follow-up or between in-person visits. In two, communication with the palliative care team was solely through structured telephone-based contacts[6,27].

2) Semi-structured consultations with a focus on both symptom management and psychosocial care

In some interventions, the visits from the palliative care team were semi-structured using a communication guide. Sometimes discussions were structured following the guidelines of the National Consensus Project for Quality Palliative care focusing not only on symptom management but also on themes like illness understanding, religion and spirituality, care preferences and coping[8,9]; other interventions used the Charting your course tool, a cognitive behavioural tool to help patients with cancer to navigate their healthcare and to cope with their disease[6,27]. In some interventions the Distress Thermometer[6,27] or the Edmonton Symptom Assessment System[8–10] were used to routinely screen cancer-related symptoms at each visit or contact.

3) Education for involved health professionals

In two interventions, information or training sessions were arranged for members of the palliative care team[6,7]. These involved a two-day training course on problem-solving and becoming familiar with the study materials[6,7].

Focus groups with PHC teams

Six teams agreed to participate in a focus group. After focus groups with six teams no new information arose and the research team judged after analysing the field notes that data saturation had been reached and no additional focus groups were arranged. Fifty-one health professionals (42 palliative care nurses, seven palliative care physicians and two palliative care psychologists) attended one of the six focus groups. A more detailed description of the methods can be found elsewhere.[28]

Based on the results of the focus groups, the key components found in the literature were adapted and supplemented for the context in Flanders.

Which patients are eligible for early palliative home care?

PHC teams were unhappy about the inclusion of all patients with an advanced oncological diagnosis because of the broad range in life expectancy and disease progression between cancer types. The participants were concerned that the introduction of palliative care to those who could live for several years would lead to negative patient and oncologist reactions and would not be of value. They suggested that when making a decision on when to initiate palliative care one should take into account the condition of the patient and their wishes and needs.

> *"What I miss, are the wishes and needs of the patients. Who says that a patient is palliative? If they do not want to see us, then we will not visit them." (FG5, R2)*

In-person consultations by the PHC team with patient and family carer

The focus group participants agreed that face-to-face consultations with the patient and the informal carer would be better for the optimal provision of care than contact by telephone. However, the frequency of consultations needs to be adapted to the needs and wishes of the person with cancer and their informal carer.

> *"You first have an introductory visit and then you evaluate the situation together with the patient and the family, to discuss the frequency of contact." (FG4, R7)*

Holistic approach

Early in the disease trajectory, psychological and existential problems might be more prevalent than pain and other physical problems which tend to increase shortly before death so in a model of early palliative care specific attention needs to be paid to them. Participants of the focus groups acknowledged that, although having limited experience with issues other than pain and physical symptoms, it was part of their role to take up psychological and existential issues.

> *"The actual request often is merely just an indication of what's below the surface, patients typically have a lot more hidden psychological and existential problems or questions. So you have to unravel the initial request and this takes time." (FG2, R3)*

Transmural collaboration with the GP as central coordinator of care

Participants of the focus groups agreed that inter-professional and transmural collaboration between the home setting and the hospital setting would be necessary in a model of integrated care. When asked about communication channels, they said they preferred personal meetings with the GP or with oncological staff, although telephone contact would be the easiest and least time-consuming method. Importantly, the GP was seen by all teams as the central coordinator of the care trajectory and according to the participants, communication between the home setting and the hospital should therefore ideally be coordinated by the GP.

> *"The GP is the captain of the ship." (FG2, R1)*

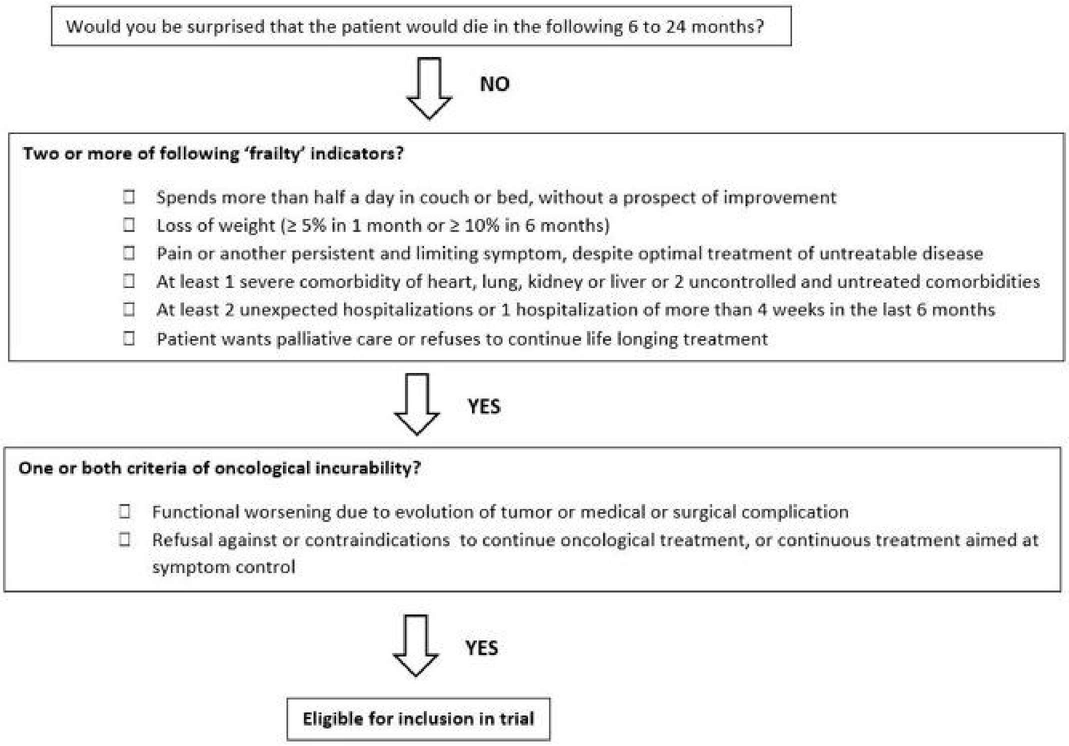
> "*In that way, being introduced much earlier, I think we will fulfil the role of palliative expert and coordinator instead of being a doer. We will be doers, but in terms of bringing people from different settings together and keeping people updated." (FG1, R3)*

Better knowledge needed of oncology and palliative care

The participants of the focus groups expressed the need for better knowledge of oncological diseases and drug therapies. They thought that health professionals working in the home context lacked the oncological knowledge needed to provide optimal palliative care concurrent with active oncology care, and that oncologists and others working in hospitals needed more information about the content of palliative care and the role a PHC team can play early in a disease trajectory.

Phase 1: modelling of the EPHECT intervention

Before the start of the intervention, oncologists in the trial are asked to screen all patients who will visit the hospital in the inclusion period having a consult with the oncologist or receiving chemotherapy for eligibility based on the diagnoses listed in the inclusion criteria. Whilst previous interventions typically focus on specific types of cancer with a limited life expectancy of one or two years, we wanted to include people with all types of solid cancers. We combined prognosis- and needs-based criteria based on the criteria of the Supportive and Palliative Care Indicators Tool (SPICT)[29] to determine which patients are eligible for early PHC (Figure 2).



Would you be surprised that the patient would die in the following 6 to 24 months?

Two or more of following 'frailty' indicators?

- ☐ Spends more than half a day in couch or bed, without a prospect of improvement
- ☐ Loss of weight (≥ 5% in 1 month or ≥ 10% in 6 months)
- ☐ Pain or another persistent and limiting symptom, despite optimal treatment of untreatable disease
- ☐ At least 1 severe comorbidity of heart, lung, kidney or liver or 2 uncontrolled and untreated comorbidities
- ☐ At least 2 unexpected hospitalizations or 1 hospitalization of more than 4 weeks in the last 6 months
- ☐ Patient wants palliative care or refuses to continue life longing treatment

One or both criteria of oncological incurability?

- ☐ Functional worsening due to evolution of tumor or medical or surgical complication
- ☐ Refusal against or contraindications to continue oncological treatment, or continuous treatment aimed at symptom control

Eligible for inclusion in trial

Figure 2: prognosis- and needs-based citeria to determine eligibility for the EPHECT intervention

Based on the results of Phase 0, EPHECT was developed with following key components (Table 3):

1) Training sessions for involved professional caregivers

Prior to the start of the intervention, all involved oncologists will be informed of the intervention in a face-to-face meeting with the researcher and data nurse. They will receive information about the working procedures and the role of the PHC team.

At the start of the intervention, the PHC team will receive a two hours training given by an oncologist consisting of group discussions, case studies and education on drug therapies and possible side effects. At the same time, the PHC team will also receive information about and be trained in the use of the conversation guide and the transmural communication scheme.

2) GP as coordinator of care

In Belgium, the GP has to grant permission that the PHC team will be introduced[21]. Furthermore, the GP will act as the coordinator of the care between the home setting and the hospital setting. Collaboration and communication between health care professionals will be organised via telephone contacts as Flanders lacks a general e-Health system.

The GPs of the patients eligible for early palliative home care will be contacted by the data nurse to inform them about their role as coordinator of the care process and will be asked to grant permission to introduce palliative home care to the patients who - based on the oncologist's screening - are eligible for early palliative home care and who agreed to participate.

3) regular and tailored home consultations by the palliative home care team

After including a patient in the intervention, a palliative care nurse from the PHC team will visit the patient at home. We recommend a minimum of one home visit per month, but frequency should be discussed with the patient in the first consultation and be tailored to their needs and wishes. The in-person consultations can be supplemented with in-between telephone contact if needed.

4) the use of a semi-structured conversation guide to facilitate consultations

We developed a semi-structured conversation guide to be used by the nurse of the PHC team to talk about topics relevant in the provision of early palliative care. The guide is based on those used in previous intervention models[6,8,10,27,30], the guidelines of the National Consensus Project for Quality Palliative Care[31] and on the process evaluation of Temel's intervention which largely addressed symptom management, patient and family coping and illness understanding and education.[32] The following topics are therefore embedded in our guide: a) understanding and perception of the illness, b) symptom management, c) organisation of care, d) coping mechanisms, e) quality of life of the patient and informal carer, f) preferences for future care. Symptom management will be performed using the Edmonton Symptom Assessment Scale (ESAS), filled out by the patient and discussed with the PHC team member at every home visit. The PHC team will use a graph to plot the development of the scores and to provide an overview of symptom fluctuation over time leading to a more structured management of pain and symptoms.[33]

After each visit, contact between the GP and the nurse of the PHC team is needed to discuss if actions linked to topics of the conversation guide are needed.

5) inter-professional and transmural collaboration

During the weekly multidisciplinary meeting of the PHC team, each patient will be discussed. To test if the intervention model is feasible in daily practice, we will use telephone contact as communication method. After each home visit, a member of the team will contact the GP by telephone. If needed, the GP will contact the oncologist to discuss further actions. The GP will thus be the coordinator of care, as he is now.

Measures of feasibility and acceptability

The primary objective of this study is to assess the preliminary effectiveness of the EPHECT intervention on the patient's quality of life measured with the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30), because previous interventions have proven a beneficial effect on quality of life.

The secondary objectives are (1) to assess the preliminary effectiveness on the patient's mood, assessed with the Hospital Anxiety and Depression Scale (HADS) and illness understanding, measured by a questionnaire developed by Temel et al. and translated by Vanbutsele et al., (2) to assess the preliminary effectiveness on informal caregivers' mood (HADS), satisfaction with care, assessed with the Family Satisfaction with End-of-Life Care (FAMCARE) and illness understanding and (3) the feasibility and acceptability of the EPHECT intervention as perceived by participating patients, family caregivers, GPs, oncologists and the PHC team.

The preliminary effectiveness of the EPHECT intervention will be assessed with questionnaires comparing patient and caregiver outcomes at baseline and after 12, 18 and 24 weeks by the data nurse. The feasibility and acceptability of the EPHECT intervention will be evaluated in interviews with participating patients, family caregivers, GPs and oncologists who participated in the

EPHECT intervention and in a focus group with the participating PHC team; and by registering the number of visits done by the PHC team, by analyzing the content of the conversations and the time spent on different topics, by registering and analysing the amount of and reasons for interprofessional contact which will all be gathered in the logbooks of the researcher, data nurse and the PHC team and in the electronic patient files.

DISCUSSION

This article describes the development and modelling process of the core components of EPHECT, an intervention aimed at supporting the early integration of palliative home care into standard oncology care. The intervention consists of five key components: 1) information sessions for involved professional caregivers, 2) GP as coordinator of care, 3) regular and tailored home consultations by the palliative home care (PHC) team, 4) the use of a semi-structured conversation guide to facilitate consultations, and 5) inter-professional and transmural collaboration.

To our knowledge, this is the first intervention developed to support the early integration of palliative home care into standard oncology care. An important strength of this study is the use of the MRC Framework for systematically developing and evaluating complex interventions[22]. This framework, following an iterative approach from the development of the intervention to its large-scale implementation, has proved to be valuable as a guide to developing, modelling and evaluating complex interventions.[34–36] It allows researchers to identify the key components of interventions and to adopt the appropriate methods for evaluating them.[22]

A model for testing the effects of early integration of specialised palliative home care into oncology care is lacking[14], but highly needed. Palliative home care increases the chances of dying at home and helps to reduce the symptom burden that people may experience due to advanced illness.[37] However, a European study shows that the median duration of palliative care services for cancer patients still only ranges from 15 days in Belgium to 30 days in Italy[4] and data from 2014 show that palliative care in Flanders is still initiated late in the disease trajectory; 60% of all interventions made by the fifteen PHC teams were initiated in the last 30 days prior to death.[38]

Our intervention model is comparable with previous interventions in terms of some key components[6–10]. The intervention includes regular home visits by palliative care nurses with a semi-structured communication guide focusing not only on symptom management but also on psychological and social care with a focus on advance care planning. A recent study shows that regular visits by the palliative team focusing not only on symptom management, but also on coping and advance care planning are associated with improved patient quality of life and lower scores on depression.[39]

However, our model differs in several respects due to a different setting and a different target population. An important aspect observed in our literature search is that most previous interventions of early palliative care focused on specific types of advanced cancer with a limited life expectancy of approximately one to two years. However, the holistic vision of palliative care as stated by the WHO[25] implies that provision should be more needs-based than prognosis-based and according to a Delphi study[40] the exact timing of early palliative care in metastatic diseases in which median survival is longer than one or two years might be a factor of need rather than based on prognosis. With the aim of incorporating a more encompassing approach, our intervention focuses on all advanced solid cancers using a combination of prognosis and needs as inclusion criteria. This is in line with a recent study[41] showing that time-based as well as needs-based criteria are seen by specialists as most important for referral to outpatient palliative care.

In our intervention, we also made adaptations to a key component found as a result of our literature search: education and training. The participants of our focus groups explicitly mentioned the need for more knowledge of oncological diseases, drug therapies and side effects to provide optimal concurrent palliative care.[28] We therefore expanded the information sessions on educational materials by adding information on oncological diseases. Furthermore, we included one additional component compared with previous interventions i.e. structured inter-professional collaboration. Transmural and inter-professional collaboration was added as an additional component. Previous interventions have mentioned that communication between oncologists and palliative care professionals is important, but did not explicitly include it as a component of the intervention.[9,30] However, only one recent intervention added structured collaboration as part of the intervention protocol by involving the palliative team in multidisciplinary meetings[42]. In our model, transmural communication will be organised by telephone contact as in Belgium a general e-Health system is still in progress.

Some limitations have to be acknowledged. Firstly, we did not perform a systematic literature review concerning the key components of a successful intervention. However, the interventions that met our inclusion criteria are the same as those described in a recent systematic literature review of key components of early palliative care for advanced cancer patients by Haun et al.[43] Secondly, the research field on integrated palliative care is rapidly developing and in the last two years additional randomised controlled models of early integration of palliative care into oncology care have been published.[42,44] However, these do not include any components that were not included in our intervention model.[42,44]

In summary, performing a phase 0-1 study according to the MRC guidance helped us to develop a model for the early integration of palliative home care into standard oncology care, which takes into account the existing evidence base and the local context. Having developed and modelled this specific intervention for the home setting, it will be important to test its feasibility and acceptability to patients diagnosed with advanced cancer and their primary carers as well as to all health care professionals involved in their care, and to evaluate its effectiveness thoroughly in a Phase II pilot study which will allow us to optimize the intervention model for further implementation.

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Phase	**Methodology**
(A) Phase 0 – theory	
(A.1) Identifying evidence base	(i) Literature search on existing interventions focusing on early integration of palliative care in oncology care
(A.2) Exploring the Flemish context of palliative home care and identifying existing barriers for early integration	(i) Focus groups with six palliative home care teams
(B) Phase 1 – modelling of EPHECT intervention	
(B.1) Selecting target population	(i) Literature search on inclusion criteria and existing tools (ii) Discussing the criteria with an oncologist
(B.2) Selection of intervention components	(i) Identification key components of existing interventions (ii) Creation of a preliminary intervention model (iii) Feedback on preliminary intervention model by oncologists and PHC team
(B.3) Improving the intervention model and increasing feasibility and acceptability	(i) Stakeholder workshops with representing patient groups, family carers, professionals working in palliative and primary care and policy makers following a participatory approach
(B.4) Finalizing the EPHECT intervention	(i) Monthly meetings with multidisciplinary research team consisting of psychologists, sociologists and a medical oncologist

Table 1: overview of phases and methods used for the development of the EPHECT intervention following the MRC Framework

Authors	**Study population – site**	**Intervention**	**Outcomes***
Bakitas et al[6]	Advanced cancer patients with prognosis of approximately 1 year – oncology clinics and outreach clinics (USA)	Educate, Nurture, Advise, Before Life Ends (ENABLE) II - Nurse-led intervention - Telephone-based study - Manual given to patient “Charting your course” with 4 topics: problem solving, communication and social support, symptom management and Advance Care Planning - Weekly for four weeks, then monthly follow up - Each session: distress thermometer - Shared Medical Appointments (SMA) by PC physician and nurse practitioner with patient and family carer Education - Nurse educators trained in problem solving / meetings with study staff / meetings with trainer and supervisor - SMA: trained by expert	*Patient* **Quality of life** Symptom intensity **Mood** *Survival* *Informal carer* N.A. *Resource use near end of life*
Bakitas et al[7]	Advanced cancer patients with prognosis of approximately 6 months to 2 years – fast track design (3 months later)	ENABLE III - Initial in-person, outpatient PC consultation with PC physician - Six structured weekly telephone sessions by nurse - Manual patient “Charting Your Course” – extra: life-review approach - Monthly follow up calls Education - Nurse coach training: self-study, review of treatment manuals and scripts, role playing with feedback	*Patient* Quality of life Symptom intensity Mood ***Survival*** *Informal carer* Quality of life **Mood** **Burden** *Resource use near end of life*
Maltoni[9]	Newly diagnosed metastatic pancreatic cancer with a life expectancy of more than 2 months – Italy	Systematic early palliative care - Specialist and nurse led intervention - First: appointment with PC specialist with predefined checklist SAME as Temel (2010) Then: follow up every 2 to 4 weeks until death	*Patient* **Quality of life** Symptom intensity Mood

		- All appointments based on General PC guidelines - Recommendations made by PC expert on decision making had to be shared by oncologist	*Survival* *Informal carer* N.A. ***Resource use near end of life***
Temel[8]	Patients with metastatic non-small cell lung cancer	Early palliative care - Meeting with member of PC team (nurse & physician) - At least monthly visits following the guidelines of the National Consensus Project for Quality PC - Special attention to physical and psychosocial symptoms, goals of care, assisting with decision making, coordination of care	*Patient* **Quality of life** Symptom intensity **Mood** ***Survival*** *Informal carer* N.A. ***Resource use near end of life***
Zimmermann[10]	Patients with advanced cancer with a prognosis of approximately 6 months to 2 years	Early palliative care - Interdisciplinary approach (PC nurse and physician) - Outpatient o Routine visits monthly with routine structured symptom assessment o Attention to ACP - Telephone-based follow up	*Patient* **Quality of life** **Symptom intensity** **Satisfaction with care** *Survival* N.A. *Informal carer* Quality of life **Satisfaction with care** ***Resource use near end of life***

Table 2: screening of the existing interventions on early palliative care for oncology patients

*The outcomes for which a statistically significant effect of early palliative care was found are marked in bold.

Phase 0		***Phase 1***
Results of literature research	Results of focus groups	Components of intervention
Regular home visits by the PC team - Once a week to at least monthly - In-person contact combined with telephone contact	- In-person contact was preferred - Monthly visits might be not enough for some patients or too much for others	- In-person consultations with patient and family caregiver - Recommendation of minimum one home visit per month, but to be discussed with patient in first consultation - Consultations can be supplemented with in-between telephone contacts if needed
GP as coordinator of care - Not addressed in existing literature because interventions developed for hospital or outpatient setting	- GP central coordinator of care, has to be the coordinator of the communication between home and hospital setting	- GP will be contacted by data nurse to give permission for introducing PHC to his/her patient - GP will then contact the PHC to plan the first visit - GP is the central coordinator of care and communicates with PHC team and oncologist
Semi-structured contacts focusing on the provision not only of symptom management but also of psychological and social care - Routine symptom screening - Communication guideline based on existing guidelines for quality palliative care or behavioural cognitive models	- Early involvement gives more time to pay attention to psychosocial and existential problems besides pain and symptom management - Already holistic approach, but home visits are not structured at this moment	- Semi-structured guide to be used in patient consultations in which following topics are embedded: ○ Understanding and perception of illness ○ Routine symptom management (ESAS at each visit)

		○ Organisation of care ○ Coping mechanisms ○ Quality of life of patient and family carer ○ Preferences for future care
Education for involved professionals - Study materials - Problem-solving and communication strategies	- Agreement on familiarity with study materials - Palliative care specialists need more information about oncological therapies and side effects to provide optimal concurrent palliative care - Oncologists need more information about content of palliative care and the role of PHC when involved early	- Educational session of two hours for members of the PHC team consisting of group discussions, case studies and education on drug therapies and side effects - Training for PHC team in working with intervention materials - Involved oncologists will be informed about working procedures and role of PHC team
Inter-professional and transmural collaboration - Mentioned in some interventions as important but without any guidelines or structure	- Preferences for personal contact between professional caregivers, although telephone contact will be the easiest way	- Collaboration and communication via telephone contacts - Patients will be discussed by the PHC team during weekly meetings - GP will be contacted after each home visit and if needed after weekly meeting - If needed, GP will contact oncologist to discuss further actions

Table 3: Description of the intervention core components to support Early Palliative Home care Embedded in Cancer Treatment (EPHECT)

APPENDIX: SUPPLEMENTARY FIGURES

Figure 1: Semi-structured conversation guide

Different topics:	**How much time have you spent on discussing the topic?**
Illness understanding and disease insight Undertaken actions for eventual discomfort:	……. min
Symptom management (use of the ESAS) Undertaken actions for eventual discomfort:	……. min
Organization of care and coping of the family caregiver Undertaken actions for eventual discomfort:	……. min
Coping: quality of life and preferences for future care Undertaken actions for eventual discomfort	……. min

PART III

Feasibility, acceptability and preliminary effectiveness of the developed intervention and a reflection on current challenges of integrating specialized palliative care in oncology

Chapter 5.

Feasibility and acceptability of early integration of palliative home care for advanced cancer patients and their health care providers. A Phase 2 mixed-methods study.

Abstract

Background: To support the early integration of palliative home care (PHC) in cancer treatment, we developed the EPHECT intervention and pilot tested it with 32 advanced cancer patients in Belgium using a pre post design. We aim to determine the feasibility, acceptability and perceived effectiveness of the EPHECT intervention.

Methods: Interviews with patients (n=16 of which 11 dyadic with family caregivers), oncologists and GPs (n=11) and a focus group with the PHC team. We further analyzed the study materials and logbooks of the PHC team. Preliminary effectiveness was assessed with questionnaires EORTC QLQ C-30, HADS and FAMCARE and were filled in at baseline and 12, 18 and 24 weeks.

Results: Patients reported feelings of safety and control and an optimized quality of life. Being introduced earlier opened space for the PHC team to focus on more than symptom management. Telephone-based contact appeared to be insufficient to support interprofessional collaboration. Furthermore, some family caregivers reported that the nurse of the PHC team was focused little on them.

Conclusion: Nurses of PHC teams are able to deliver early palliative care to advanced cancer patients. However, more attention needs to be given to family caregivers as caregiver and client. Furthermore, the home visits by the PHC team have to be further evaluated and adapted. Lastly, professionals have to find a more efficient way to discuss future care.

INTRODUCTION

The World Health Organization (WHO) advises to provide palliative care early in the course of a life-threatening illness – i.e. from diagnosis of advanced cancer on –, in conjunction with other therapies that are intended to prolong life.[1] Similarly, the American Society of Clinical Oncology (ASCO) and the Multinational Association of Supportive Care in Cancer (MASCC), the European Society of Medical Oncology (ESMO) and the European Association of Palliative Care (EAPC) in Europe also recommend palliative care to be introduced early in the disease trajectory concurrent with active treatment for advanced cancer patients with a life expectancy of 6 to 24 months.[2]

Over the past few years, a growing number of studies have investigated the effects of integrating palliative care early in oncology care on the quality of life of patients.[3–10] Most studies showed a positive effect, but all focused on integrating early palliative care in cancer treatment in the hospital or in the outpatient setting. Up till now, no studies have been published on integrating palliative care early at home. Palliative care is indeed not only provided in hospitals or via outpatient clinics but also and especially at home. A recent systematic literature review shows that the majority of cancer patients prefers to die in their own homes[11] and palliative home care allows people to stay at home until death, supported and surrounded by those close to them[12]. However, integrating palliative *home* care into standard oncological treatment is more complex than early integration in hospital or outpatient clinics, as it requires interprofessional and transmural collaboration – i.e. collaboration between multidisciplinary teams at home and in hospital. Hence, there is a need for an evidence-based model for the early integration of palliative home care in the current regular cancer treatment for advanced cancer patients that takes account of these complexities.

To facilitate the early integration of palliative *home* care in cancer treatment, we developed the Early Palliative Home Care Embedded in Cancer Treatment intervention (hereinafter – EPHECT intervention)(Table 1).[13] Because the EPHECT intervention is one of the first interventions worldwide focusing on the early integration of palliative home care in oncology care in the hospital, it is important to first evaluate the feasibility, acceptability and preliminary effectiveness of this intervention in a phase 2 study before testing its effectiveness in a large-scale phase 3 randomized controlled trial (RCT). In this paper, we present the results of our phase 2 study providing essential information about the strengths and weaknesses of this specific intervention, and insights about how an existing multidisciplinary service of palliative home care can be optimally introduced and integrated early in a trajectory of advanced cancer.

The aims of this study are (1) to assess the feasibility and acceptability of the study procedures (i.e. recruitment, inclusion criteria) (2) to assess the feasibility and acceptability of the components of the EPHECT intervention, according to patients, family caregivers and healthcare professionals; and (3) to explore preliminary effectiveness and perceived effects of the EPHECT intervention on the quality of life of patients and family caregivers.

METHOD

Study design

We designed a phase II pre-post trial following the guidance of the Medical Research Council for the development and evaluation of complex interventions[14,15]. To assess feasibility and acceptability of the intervention components, we conducted interviews with patients, family caregivers, general practitioners (GPs) and oncologists and a focus group with the palliative home care (PHC) team after the intervention. Patients and family caregivers also had to fill in questionnaires at baseline and at 12, 18 and 24 weeks follow-up to evaluate the preliminary effectiveness of the intervention.

Table 1: overview of the components of the EPHECT intervention

Component	Description
Education of involved professionals of the palliative home care team	- Educational session of two hours for members of the PHC team consisting of group discussions, case studies and education on drug therapies and side effects - Training for the PHC team in working with the intervention materials
Information of involved oncologists	- Involved oncologists are informed about the intervention and the role of the PHC team
General practitioner (GP) as coordinator of care	- GP were contacted by data nurse to give permission for introducing PHC to his/her patient - GP then contacted the PHC team to plan the first visit - GP is the central coordinator of care and communicates with the PHC team and oncologist
Regular home visits by the nurse of the palliative home care (PHC) team	- In-person home visits with patient and family caregiver - Recommendation of minimum one home visit per month, but to be discussed with patient in first consultation - Consultations supplemented with in-between telephone contacts if needed

Semi-structured home visits not only focusing on symptom management, but also on psychological and social care	- Semi-structured conversation guide used in home visits of the PHC team in which following topics are embedded: o Understanding and perception of illness o Routine symptom management (ESAS at each visit) o Organization of care o Coping mechanisms o Quality of life of patient and family caregiver o Preferences for future care
Interprofessional and transmural collaboration	- Collaboration and communication via telephone contacts - Patients discussed by the PHC team during weekly meetings - GP should be contacted after each home visit and if needed after weekly meeting - If needed, GP should contact oncologist to discuss further actions

After oncologists screened patients for their eligibility for the study (see table 2 for inclusion criteria), the data nurse introduced the EPHECT intervention to all eligible patients and asked whether they were willing to participate. When patients agreed to participate and filled in an informed consent, the data nurse contacted their GPs because in Belgium the GP has to give permission to the PHC team to start a trajectory with a patient. More details about the content and development of the EPHECT intervention can be found in Table 1 and elsewhere[13].

Similar to previous models of early palliative care in the hospital, the EPHECT intervention consists of regular visits of the palliative care team to the patient, in this case at home, supported by a semi-structured conversation guide focusing on symptom management, psychological and social care. The EPHECT intervention also incorporates a structured procedure by telephone contact (see table 1) for collaboration between the health care settings, a component that is more complex and elaborated compared with the other existing models as integrating palliative home care requires collaboration between settings of home (self-care and family caregivers), primary care (GPs) and the hospital care (oncologists, oncology nurses, etc.).

We used the Consolidated Standards of Reporting Trials (CONSORT) guidelines as a methodological guidance for reporting the EPHECT intervention[16].

Settings and participants

This study was performed in the home setting of advanced cancer patients in the Brussels region. We recruited patients with advanced cancer from the Medical Oncology departments of a university hospital and a general hospital. All patients in treatment and all newly diagnosed patients with a solid cancer diagnosis were screened in the hospitals by the oncologists for their eligibility (table 2).

Table 2: inclusion and exclusion criteria

Inclusion	Exclusion
- Non-curative treatable solid cancer diagnosis - Life expectancy of 6 to 24 months (assessed by treating oncologist) - Identification as having palliative needs (assessed by treating oncologist) - Active anticancer treatment - 18 years or older - Patients with the ability to read and respond to questions in Dutch	- Hematological malignancy as primary diagnosis - Not housed in the Brussels region - No active anticancer treatment - No permission of the GP - More than one palliative care consultation with palliative team in hospital before inclusion - Involved in another palliative care intervention study - Impaired cognition

The Ethics Committees of the University Hospital and of the regional hospital approved the study protocol. All patients, informal caregivers and GPs involved in the study provided their written informed consent.

Data collection

An overview of the methods to assess the feasibility, acceptability and preliminary effectiveness of the EPHECT intervention can be found in table 3.

- *Feasibility and acceptability of the study procedures* was assessed by registering the number of all eligible patients (and reasons for being not eligible), patients who were asked to participate in the study, and patients who agreed to participate (and reasons for non-participation). We also registered drop out during the study (and reasons for drop out), and time of death. Information about time of death was collected from medical records and information about the recruiting procedure was kept in the logbooks of the researcher and the data manager.
- *Feasibility of the intervention* was assessed quantitatively, by registering the number and duration of the visits done by the PHC team. The content of the conversations and the estimated time spent on the topics described in the semi-structured conversation guide were collected by the nurses of the PHC team in the electronic patient file. They also

registered the amount of and reasons for contact of the PHC team with other professional caregivers in the logbook for transmural collaboration. Nurses of the PHC team were asked to keep a record of contacts with GPs and oncologists in the care for a patient. The contacts between GPs and oncologists were evaluated in the semi-structured interviews with GPs and oncologists.

- *Acceptability of the intervention* was assessed with qualitative methods, i.e semi-structured interviews with patients, family caregivers, GPs and oncologists involved in the intervention. Interviews with patients, family caregivers and GPs focused on perceived strengths, concerns and weaknesses of the intervention and whether the intervention was acceptable. Interviews with oncologists focused on exploring strengths and weaknesses of the intervention, and on their own role within the intervention including their reflection on the inclusion criteria. We also conducted a focus group with the PHC team involved in the intervention, focusing on their experiences with the intervention and the usability of the intervention materials.
- The *preliminary effectiveness of the intervention* was assessed with questionnaires for patients and family caregivers by comparing patient and caregiver outcomes at baseline and after 12, 18 and 24 weeks. The primary outcome was the patient's quality of life measured with the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30)[17]. Secondary outcomes were (1) the patient's mood, assessed with the Hospital Anxiety and Depression Scale (HADS)[18] and illness understanding, measured by a questionnaire developed by Temel et al.[5] and translated by Vanbutsele et al.[19], (2) the informal caregivers' mood (HADS), satisfaction with care, assessed with the Family Satisfaction with End-of-Life Care (FAMCARE)[20] and illness understanding.
- We also assessed *perceived effectiveness of the intervention* in the interviews with patients, family caregivers, GPs, oncologists and the focus group with the PHC team.

Table 3: overview of methods to assess feasibility, acceptability and perceived effectiveness of the EPHECT intervention

MEASURES	METHOD	INDICATORS
Feasibility study procedures	Logbooks researcher & data nurse Electronic patient file	Inclusion procedure Drop out & time of death Questionnaires • Missings • Responses at baseline and follow-up
Feasibility & acceptability intervention	Quantitative: • Logbooks Omega • Record of time spent on topics of the semi-structured guide in electronic patient file • Record of interprofessional contact in electronic patient file Qualitative: • Interviews with patients and family caregivers, GPs and oncologists • Focus group with PHC team	Quantitative: • Amount and content of visits • Time spent on topics of the semi-structured guide • Interprofessional contact Qualitative: • Acceptability of the intervention components • Suggestions for improvement
Preliminary and perceived effectiveness	Quantitative: • Questionnaires filled in by patients and family caregivers at baseline and follow-up at 12, 18 and 24 weeks Qualitative: • Interviews with patients and family caregivers	Quantitative: • Patient ○ Quality of life (EORTC QLQ C-30) ○ Mood (HADS) ○ Disease insight • Family caregiver ○ Satisfaction with care (FAMCARE) ○ Mood (HADS) ○ Disease insight Qualitative: • Patients' and family caregivers' perceived effects of the EPHECT intervention

Data analysis

Qualitative data

A topic guide for the interviews and the focus group, consisting of open questions and a set of prompts, was developed by a member of the research team (ND) and reviewed within a multidisciplinary team of researchers. Interviewers were a member of the research team (ND) and a data manager (FS).

All interviews and the focus group were audio-recorded, transcribed verbatim and analysed by a junior and a senior researcher (ND and TS). Interviews were analysed both by induction (thematic content analysis using codes on the basis of the underlying structure of the interview) and deduction (using the intervention components as framework).

Qualitative data analysis software (NVivo 11) was used.

Quantitative data

We included all data collected during the study period. We calculated mean and standard deviations for each questionnaire at t0, t1, t2 and t3. The mixed-effects linear model for repeated measures represents a proper statistical method to assess possible changes in scores over time, allowing for differing numbers of measures per patient and accounting for missing values, by incorporation of all available data into a single model spanning the entire follow-up period. These characteristics make this model ideal for investigating the changes over time.

RESULTS

Feasibility and acceptability of the study procedures

Inclusion & drop out of patients

From October 2017 to February 2018, all patients with advanced cancer receiving active oncological treatment in the two involved hospitals were screened for eligibility by all oncologists. The EPHECT intervention was introduced by the data manager to 41 eligible patients of which 39 consented to participate and filled in a questionnaire at baseline. Of those 39 patients, 7 patients died and 2 dropped out between baseline measurement and the first visit of the PHC team four weeks later. The 2 patients who dropped out were not convinced of the added value of the intervention. A flowchart of the study can be found in figure 1.

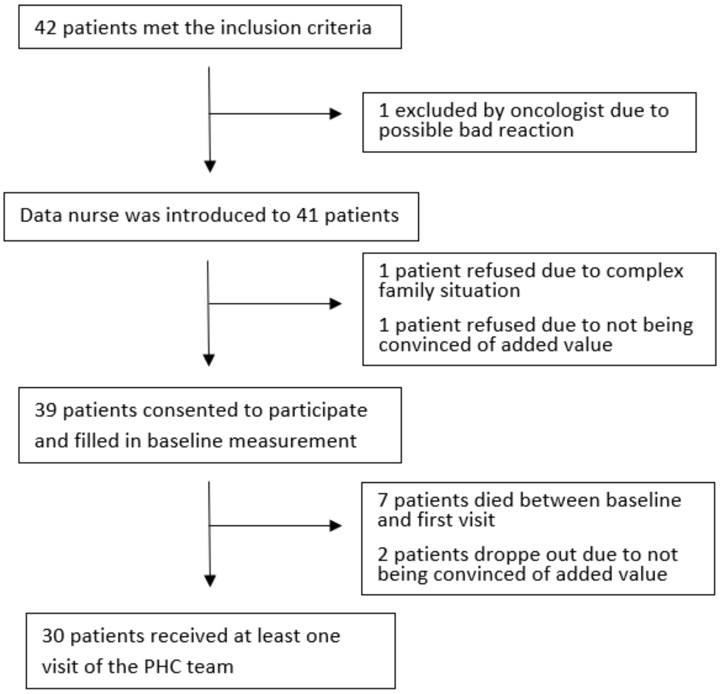

Figure 1: flowchart of the study

Thus, 30 of the 41 eligible patients (73%) were visited at least once by the PHC team. Characteristics of those 30 patients are presented in table 4. The most common cancer type was digestive cancer (47%), followed by lung (17%) and Triple Negative breast cancer (17%). 26/30 patients (86,6%) filled in the questionnaire at 12 weeks, 21/30 (70%) at 18 weeks and 18/30 (60%) at 24 weeks. Most of the patients who dropped out during the 24 weeks died, 2 patients dropped out due to personal reasons.

Of those 30 patients, 13 included a family caregiver who gave consent and also filled in a questionnaire at baseline, 12, 18 and 24 weeks. Drop out in family caregivers during the intervention period was directly linked to drop out in patients.

Table 4: patient characteristics at baseline (N=30)

	N	%
Age		
18-65	15	50%
> 65	15	50%
Gender		
Male	18	60%
Female	12	40%
Living situation		
Home (cohabiting)	26	86,7%
Home (alone)	4	13,3%
Partner		
Yes	27	90%
No	3	10%
Highest level of education		
Lower than high school	3	10%
Lower level in high school	11	36,7%
Higher level in high school	10	33,3%
College, university	6	20%
Primary cancer diagnosis		
Digestive	14	46,7%
Breast cancer triple negative	5	16,7%
Lung	5	16,7%
Gynecological	3	10%
Sarcomas	1	3,3%
Head-neck	1	3,3%
Prostate	1	3,3%

Feasibility of inclusion and exclusion criteria

All 5 oncologists reported in the interviews that it was easier to estimate a life expectancy of six months than two years. Instead of using prognosis as primary inclusion criterium, oncologists suggested to introduce palliative home care from diagnosis of an advanced disease. Two made an exception for breast cancer because those patients could live for five or ten years with metastases. They suggested to introduce palliative home care to those patients after two lines of chemotherapy. Some patients mentioned that they would have liked palliative home care to be introduced even earlier in the disease trajectory because it would have created more time and space for building up a relationship with the PHC nurse.

Feasibility and acceptability of used questionnaires

Only 60% of the participants filled in questionnaires at 24 weeks. However, most of those patients had died and some dropped out due to personal reasons. All patients that were still participating at 12 weeks, filled in the questionnaires as it was asked. The interviews with patients and family caregivers showed that the amount of questionnaires and the duration to fill them in was acceptable and feasible.

Feasibility and acceptability of the intervention components

Only one GP was suspicious in the beginning about the added value of visits by the PHC team for his patient. However, all GPs eventually gave permission to include their patients in the EPHECT intervention.

Education for nurses of the PHC team

Although nurses of the PHC team had the possibility to ask questions about oncological diseases and treatments in the information sessions, they had the feeling in the first home visits that they did not know enough to answer questions about oncology care. Instead of answering these questions, they empowered the patients in asking the questions to the oncologist on the first following consultation. Despite nurses' feelings of uncertainty about their ability to handle issues related to diagnoses, prognoses and oncological treatments at the beginning of the intervention period, interviews with patients and family caregivers showed that the nurse of the PHC team often provided information about diagnosis and prognosis if needed and the nurses confirmed that experience with early palliative care trajectories was important in increasing their self-efficacy.

Regular home visits by the PHC team

During the six-month intervention period, nurses of the PHC team visited the patients on average four times. Six patients were visited only once, five of them died before the second visit and one patient found the visits too time-consuming and not useful. Ten of 30 patients were visited monthly as recommended in the intervention protocol, resulting in six or more visits. Reasons that members of the PHC team gave for visiting patients less often or not monthly were that sometimes patients were admitted to the hospital and visits had to be rescheduled to a later time. Some visits to the patient's home were replaced by a telephone call when the patient did not need a home visit for instance when they stabilized or their condition improved. More frequent visits (more often than once a month) occurred when the patient's health condition got worse or when the patient was closer to death.

The 15 interviews with patients and family caregivers showed that they did not have problems with being involved in palliative home care whilst receiving ongoing anticancer treatment and that visits were considered necessary monthly in the beginning of the trajectory for building a trusting relationship. Most patients found that once this relationship was established, monthly visits were acceptable but not needed and most patients were glad that the visits were planned by the PHC team. Some patients told that they would not contact the PHC nurse by themselves even though they evaluated the visits as beneficial. The main reason for this lack of taking initiative was that patients had other things to worry about than contacting the PHC nurse. If their health condition would stabilize or improve, some patients in that case recommended to plan PHC visits according to their needs. In the focus group the PHC team agreed for future care on planning the visits in dialogue with the patient and the family caregiver, whilst following them up by telephone.

Semi-structured conversation guide

Most nurses evaluated the conversation guide as a useful tool to structure the conversations with the patient during the home visits and to reflect back with the patient and family caregiver on what was discussed during previous home visits. Few patients noticed that the visits were always structured in the same way, but it did not bother them.

Content analyses of the patient files show that the home visits lasted approximately one hour, of which 30% of the time was spent on symptom management, 27% on disease insight, 25% on coping and 18% on the quality of life of the family caregiver. One third of the time was still spent symptom management, ome patients reported that the nurse of the PHC team had given them and the GP advise on medication use. But, analyses of the patient files also showed that being involved earlier gave the nurses of the PHC team the opportunity to provide holistic care and to spend more time on topics other than symptom management like disease insight – reflecting on what the patient knows about his/her disease, treatment and prognosis –, coping with the illness and the treatments and advance care planning. Members of the PHC team revealed in the focus group that they were initially concerned that providing more holistic care would require a different approach and different skills, but the more experience they gained with the intervention, the more they felt it was their responsibility to discuss not only physical symptoms, but also preferences for future care, coping or other psychosocial issues. According to patients and to the nurses of the PHC team, psychosocial and existential issues were indeed also important topics in the home visits with the patient. One patient received support and advise for sexual problems, others reported support on financial and practical level. The PHC team also talked with the patients about diagnoses and prognoses, information that was sometimes not provided clearly enough by the oncologist or not fully understood by the patient.

Lastly, analyses of the interviews showed that during the home visits, little attention was given to how the family caregiver was coping. Although most family caregivers reported that they had received enough support of the PHC team, some mentioned that the nurse of the PHC team was mainly focused on the patient and that they had expected to be involved more.

Interprofessional and transmural collaboration with the GP as coordinator of care

Analyses of the logbooks of the PHC team show that for most patients, the GP was only contacted once by a nurse of the PHC team, namely when palliative home care was initiated, to let the GP know that the PHC team was introduced to the patient. This contact was always by telephone. Only for a few patients the GP was contacted more regularly, mostly when the patient deteriorated and was in the terminal phase of life or when medication had to be adjusted. GPs therefore said that it was difficult to take up their responsibility in being the coordinator of the care trajectory. The PHC team rarely contacted the oncologist directly because they did not want to pass-by the GP.

Interviews with GPs and oncologists and the focus group with the PHC team showed that PHC teams evaluated contact with the GP as unneeded when a patient was stable, whilst GPs reported that they would have liked to receive a short report after each visit from the PHC team. The interviews also revealed that GPs as well as nurses of the PHC team were sometimes difficult to reach by telephone resulting in suboptimal interprofessional communication and collaboration. Furthermore, the majority of the GPs mentioned in the interviews that they preferred being the communicator between the PHC team and the oncologist, whilst all oncologists preferred to receive information directly from nurses of the PHC team so that they could react immediately.

Based on the feasibility and acceptability of the intervention components, we made suggested changes to the EPHECT intervention which are shown in table 7.

Preliminary effectiveness of the EPHECT intervention

Table 5 and table 6 show results of preliminary effectiveness of the EPHECT intervention on quality of life, mood and satisfaction with care. No significant deterioration nor improvement over time was observed for any questionnaire scales and subscales. Initial scores of family caregivers on the anxiety scale were high and remained high during the intervention.

Patients’ and family caregivers’ perceived effects of the EPHECT intervention

Safe haven

The first visits of the PHC team were mainly used to build up a relationship with the patient and the family caregiver. Although the health condition of most patients was stable when the PHC team first visited them, patients and family caregivers evaluated the visits as positive. They reported in the interviews that having the support of the PHC team whilst receiving chemotherapy resulted in feelings of safety and trust. Especially family caregivers felt safe because they knew who they could turn to when their beloved one's condition would deteriorate.

Quality of life

Almost all patients reported that the EPHECT intervention had a perceived positive effect on their quality of life by interventions done or advised by the nurse of the PHC team to relieve discomfort and to optimize their symptom management.

Communication between patient and family

Some patients and family caregivers felt that the nurse facilitated conversations, especially when they were not used to talk to their partner or family about their worries. One oncologist said in the interview that the EPHECT intervention was of great value for a patient and her family because it brought the family together and facilitated communication about the dying process.

Empowerment and advance care planning

Some patients mentioned that the visits of the nurse of the PHC team helped them in reflecting on their wishes and needs and in discussing them with other professional caregivers. Two oncologists also reported that they had the feeling that patients who participated in the EPHECT intervention became more assertive in stating their wishes for future care and communicating their concerns than they were before the start of the intervention.

DISCUSSION

Main findings

This study shows that early integration of palliative home care in oncology treatment is feasible and accepted for the most part by patients, family caregivers and professional caregivers. Most of the participating patients, family caregivers and professional caregivers valued the visits of the PHC team. Patients experienced feelings of empowerment, safety and control and reported to have received support to optimize their quality of life. However, important challenges were found with some of the study components that had an influence on the feasibility and acceptability of the intervention. Telephone-based contact appeared to be insufficient to support collaboration between disciplines and settings. Furthermore, the GP was not involved more in the care trajectories than before the EPHECT intervention and in most cases he or she had difficulties with practicing the role of coordinator of care.

Discussion of the main findings

The drop-out of patients due to death during the intervention period is striking given the inclusion criterium of having an estimated life expectancy of 6 to 24 months. All participating oncologists reported that it was possible to estimate a life expectancy of 6 months, but they found a life expectancy of 24 months more difficult to predict. Previous research also shows that it can be difficult for oncologists to estimate survival and that oncologists might have the tendency to be overly optimistic[23–25]. Another possible explanation is that oncologists might have deliberately included patients with a shorter life expectancy out of fear to deprive the hope of patients with a longer estimated survival time, which has been reported as a barrier for early integration of palliative home care in several previous studies[26–32].

The protocol of the EPHECT intervention included monthly consultations with a nurse of the palliative home care (PHC) team. However, two thirds of the participants received fewer consultations; the nurse of the PHC team visited the patients on average four times in the 6-month intervention period. According to patients and family caregivers as well as according to the PHC team, systematic visits are important at the beginning of the trajectory because these visits allow to build a relationship of trust. Once the relationship is built, monthly consultations are acceptable to patients but not necessary as long as the patient's situation is stable. In our intervention protocol, we recommended to plan monthly visits to patients based on previous interventions showing a positive effect of systematic and early integration of palliative care on patient-reported outcomes.[3–5,7,9,10,33] However, it remains unclear if continuing systematic consultations at home is more effective than follow-up consultations by telephone as used in the ENABLE interventions wherein structured telephone sessions were organized by a PC nurse[3,4]. Future research is needed to investigate the optimal frequency, structure and implementation of palliative care consultations to improve the quality of life of patients with advanced cancer.

The home visits by the nurse of the PHC team were mainly focused on symptom management and illness understanding, but also psychosocial and existential issues were addressed, which confirms findings of previous intervention studies on early palliative care.[34–36] As expected by the focus groups with PHC team in our previous research[37], psychological issues are more prominent earlier in the disease trajectory. At the beginning of the intervention period the nurses of the PHC team feared that they would not be able to manage these issues because their previous experience was mainly focused on acute symptom management[37]. However, their self-efficacy increased during the intervention. In the information sessions for nurses of the PHC team we did not focus on communication but to be prepared for and feeling safe in having these conversations, we would recommend to take this into account in future trainings for palliative care teams.

This study also found that some family caregivers had the feeling that the visits of the nurses of the PHC team were mainly focused on the patient and that sometimes little attention was given to how family caregivers were coping with the disease of their beloved one. Furthermore, analyses of the HADS questionnaire for family caregivers show that initial scores on anxiety were high and remained high during the intervention period. Looking at previous existing interventions, explicit advise and guidelines on involving the family caregiver were rarely made. In the EPHECT intervention coping of the family caregiver was integrated in the semi-structured conversation guide as a topic needed to be discussed. However, analyses of the logbooks of the team confirm that this topic was the least discussed one during the conversations.

Family caregivers are often defined as unpaid, informal providers of care who have a personal connection to the patient and provide – especially when patients want to be cared for at home – one or more physical, social, practical and emotional tasks. By doing this, they are important actors in providing holistic palliative care[38]. However, taking up these tasks can cause anxiety and other several needs that are often undertreated or not addressed[39-41]. Palliative care teams need to focus more on supporting the family caregiver in caring for their beloved one, as well as taking care of their own needs.

Our intervention results shows that telephone-based contacts mostly failed to improve interdisciplinary and transmural collaboration. A recent influential Commission paper states that a multidisciplinary team approach, with systematic collaboration among team members from different professions within and across levels of care, is needed to strive for optimized integrated palliative care.[42] A systematic review on interventions focusing on integration and oncology care reveals that of the seven included only one advised to routinely involve palliative care teams in multidisciplinary tumor conferences and in only three of them communication and collaboration between the palliative and the oncological service was established[43-44]. There needs to be a shift from coordinated care in which different teams are linked but working in separate structures to integrated care, in which professionals from different disciplines and settings are gathered together to discuss future care goals. To strive for optimized integrated care, the EPHECT intervention needs to be adapted on interprofessional collaboration.

Strengths and limitations

Performing a phase 2 study is more cost-effective than immediately carrying out a large-scale phase 3 RCT. Based on the results of this phase 2 study necessary adaptations can be made on the intervention model before testing it in a trial with a larger study population. Furthermore, conducting interviews with patients, family caregivers and professional caregivers provided clear insights on the feasibility and acceptability of the EPHECT intervention. However, several limitations exist with regards to the design of this intervention. First, by conducting a pre post design, we had no control group. This makes it difficult to make assumptions about the trends seen in patient and family caregiver outcomes. Second, because of the complex nature of the intervention, it is not possible to make conclusions about the effectiveness of individual components.

Conclusion

This study shows that early integration of existing palliative home care in oncology treatment is feasible and accepted for the most part by patients, family caregivers and professional caregivers. By making only small adjustments to current practice, nurses of PHC teams are able to deliver palliative care to advanced cancer patients before they are terminally ill. However, this phase 2 pre-post study also provides essential information on how the EPHECT intervention can be optimized before testing its effectiveness in a large-scale phase 3 RCT. More attention needs to be given to the support of the care giving by family caregivers and to health care provision of family caregivers. Furthermore, the optimal frequency and structure of the home visits by the nurse of the PHC team have to be further evaluated and adapted. More challenging is the optimization of the integration model. To strive for optimized integrated palliative care, professional caregivers from different disciplines and settings have to find a more efficient way to discuss commonly future care goals.

Table 5: evolution of mean scores over time in quality of life and mood of patients with advanced cancer at baseline, 12, 18 and 24 weeks

Patients' outcomes	Range	Assessment				
		Baseline (t0)	12 weeks (t1)	18 weeks (t2)	24 weeks (t3)	
		(N = 30)	(N = 26)	(N = 22)	(N = 18)	
		Mean ± SD	Mean ± SD	Mean ± SD	Mean ± SD	*P value*
EORTC QLQ C-30						
Global QOL	0-100	60,5 ± 16	58 ± 17,7	61,9 ± 17,6	62,5 ± 17,2	0,81
Physical functioning	0-100	60,9 ± 23,8	60,5 ± 23,2	60,9 ± 21,2	65,4 ± 23,1	0,90
Role functioning	0-100	59,4 ± 31,5	51,3 ± 29,6	53 ± 28	55,6 ± 32,8	0,78
Emotional	0-100	69,6 ± 18,3	66 ± 24,6	67 ± 23,4	70,8 ± 24	0,88
functioning	0-100	75 ± 23,1	68 ± 25,4	75 ± 25,1	69,4 ± 29,8	0,67
Cognitive	0-100	72,2 ± 23	73,1 ± 20,6	75,8 ± 19,1	69,4 ± 29,8	0,86
functioning						
Social functioning						
HADS						
HADS – anxiety	0-21	7,9 ± 4,1	7 ± 4	6,2 ± 4,3	7,5 ± 5,1	0,55
HADS – depression	0-21	7,4 ± 3,6	7,3 ± 4,3	6,6 ± 3,7	7,1 ± 4,5	0,90

EORTC QLQ C-30: European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (for all the EORTC QLQ C-30 scales the higher the score, the better quality of life); HADS: Hospital Anxiety and Depression Scale (for both HADS subscales the higher the score, the higher the distress)

Table 6: evolution of mean scores over time in satisfaction with care and mood of family caregivers at baseline, 12, 18 and 24 weeks

Caregiver outcomes	Range	Assessment				
		Baseline (t0)	12 weeks (t1)	18 weeks (t2)	24 weeks (t3)	
		(N = 13)	(N = 12)	(N = 9)	(N = 7)	
		Mean ± SD	Mean ± SD	Mean ± SD	Mean ± SD	*P value*
FAMCARE						
Total score	0-100	70,7 ± 9,9	70,5 ± 13,7	70,6 ± 12,9	71,4 ± 17,5	0,99
HADS						
HADS – anxiety	0-21	10,5 ± 4,5	10,5 ± 4,6	10,3 ± 3,7	11,3 ± 6,3	0,98
HADS – depression	0-21	8,5 ± 2,5	8,2 ± 4,4	6,6 ± 4,5	7,3 ± 5	0,73

FAMCARE: Family Satisfaction with End-of-Life Care (higher score means higher satisfaction with care); HADS: Hospital Anxiety and Depression Scale (for both HADS subscales the higher the score, the higher the distress)

Table 7: suggested changes to the EPHECT intervention

Component	Description	Acceptability and feasibility	Suggested changes to the intervention
Education for involved professionals	- Educational session of two hours for members of the PHC team consisting of group discussions, case studies and education on drug therapies and side effects - Training for the PHC team in working with the intervention materials - Involved oncologists will be informed about the intervention and the role of the PHC team	- Training was too short to make nurses of the PHC team comfortable in having discussions on oncology care	- Ongoing educational sessions or possibilities to contact oncologists if questions about oncology care arise. - Educational sessions should focus more on involving the family caregiver.
General practitioner (GP) as coordinator of care	- GP will be contacted by data nurse to give permission for introducing PHC to his/her patient - GP will then contact the PHC team to plan the first visit - GP is the central coordinator of care and communicates with the PHC team and oncologist	- GP was rarely contacted by the PHC team, because the nurses of the PHC team thought it was not needed to contact the GP if the patient was stable. - GPs reported difficulties in taking up the role of coordinator of care because they were not involved more than in standard care.	- Clear agreements have to be made about how and when communication has to take place, in dialogue with the involved GPs, PHC team and oncologists.
Regular home visits by the palliative home care (PHC) team	- In-person consultations with patient and family caregiver - Recommendation of minimum one home visit per month, but to be discussed with patient in first consultation - Consultations can be supplemented with in-between telephone contacts if needed	- Patients, family caregivers and nurses of the PHC team said that it was necessary to install monthly visits in the beginning of the trajectory to build up a relationship. - Once the relationship is built, monthly visits are not needed as long as the situation is stable and visits should be planned	- Monthly consultations at the beginning of the trajectory. - Later on: visits need to be planned according to the needs of patients and family caregivers.

		according to the needs of the patients and family caregivers.	- Regular follow-up by telephone on initiative of the PHC team.
Semi-structured contacts not only focusing on symptom management, but also on psychological and social care	- Semi-structured conversation guide to be used in home visits of the PHC team in which following topics are embedded: o Understanding and perception of illness o Routine symptom management (ESAS at each visit) o Organization of care o Coping mechanisms o Quality of life of patient and family caregiver o Preferences for future care	- Being involved earlier provided nurses of the PHC team time to not only focus on symptom management, but also on other core domains of palliative care as recommended in the semi-structured conversation guide. - Coping of the family caregiver was the topic least discussed and some family caregivers reported in the interviews that they had the feeling during the intervention that the nurse of the PHC team was mainly focused on the patient.	- More attention needs to be given to the family caregiver in the home visits.
Interprofessional and transmural collaboration	- Collaboration and communication via telephone contacts - Patients will be discussed by the PHC team during weekly meetings - GP will be contacted after each home visit and if needed after weekly meeting - If needed, GP will contact oncologist to discuss further actions	- Telephone-based contact was insufficient. - GPs and nurses of the PHC team had different opinions about when contact was needed. - GPs wanted to be the communicator between the PHC team and the oncologist, but were rarely contacted. Oncologists reported to prefer direct contact with the nurses of the PHC team.	- Face-to-face contact between all professional caregivers needs to be installed to discuss future care. - Clear agreements have to be made about how and when communication has to take place, in dialogue with the involved GPs, PHC team and oncologists.

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Chapter 6

Early enrollment of patients with active oncological treatment into palliative home care: lessons from a phase II trial.

Abstract

Background: Early palliative care interventions have beneficial effects on the quality of life of patients and family caregivers. However, little is known about patients' and family caregivers' perceptions on being introduced to an early palliative care intervention and if participating influences attitudes towards palliative care.

Aim: To explore how the early palliative care intervention was received by advanced cancer patients and family caregivers and if participating changed their perception of palliative care. Further, to explore ideas on when palliative home care should be initiated.

Method: Qualitative content analyses of semi-structured individual interviews.

Results: Most participants had negative and skeptical emotions when introduced to the intervention. However, during and after patients became more positive about the content of palliative care. Despite positive experiences, patients remained skeptical and uncomfortable with 'palliative' because they kept associating the word with dying. According to oncologists, calling palliative care supportive care could remove a barrier to introduce it to patients and for patients to accept it. Further, professional caregivers as well as patients and family caregivers found it appropriate to introduce palliative care from diagnosis of advanced cancer on.

Conclusion: It is possible but challenging to initiate early palliative home care to patients and family caregivers. Renaming palliative care might reduce barriers for professional caregivers to introduce palliative care. However, more effort is needed to establish changes in attitudes towards palliative care. It is recommended to introduce palliative home care from diagnosis on to make palliative care part of standard care for patients with advanced cancer.

INTRODUCTION

Palliative care should be initiated early in the course of a non-curative oncological illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy.[1,2] A growing number of studies have indeed shown that offering palliative care early on and integrated into oncological treatments has beneficial effects on the patient's quality of life and mood, and improves satisfaction with care of patients and family caregivers[3–8].

Despite these beneficial effects of early palliative care on patient and caregiver outcomes, referrals to specialized palliative care services are typically executed only late in the disease trajectory.[9–11] Studies have identified several reasons for this. One of the main reasons is the societal perception that palliative care equals "terminal care", leading to a negative attitude of patients to palliative care and to a possible resistance of professional caregivers to refer patients early to specialized palliative care.[12–15] Another reason is that oncologists often find it difficult to estimate how oncological trajectories will progress and how to decide on the 'right time' to introduce palliative care, especially when the patient is still in a good physical condition or responds well to anti-cancer treatment.[16]

Research has proven that integrating palliative care in the hospital setting has beneficial effects, however, palliative care is not only provided in hospitals or outpatient clinics but also at home, allowing people to stay at home, increasing the chances of dying at home[17–19]. Despite the possible advantages of early integration of palliative home care for patients with advanced cancer, an evidence-based intervention model to integrate palliative home care early into oncology care was lacking.

Therefore, the Early Palliative Home Care Embedded in Cancer Treatment (EPHECT) intervention was developed to integrate palliative home care into oncology care in Flanders, Belgium[20]. Nurses of the specialized PHC team visited the patients monthly in their home, and were supported by a semi-structured conversation guide focusing on symptom management, psychosocial issues, coping of the family caregiver and preferences for future care[20]. The EPHECT intervention was subsequently tested in a Phase 2 pre-post study for feasibility and acceptability.

We wanted to know how the intervention was received by advanced cancer patients and their family caregivers and if participating in the EPHECT intervention changed the perception on the content and purpose of early palliative home care of patients, family caregivers and professional caregivers. We further wanted to know patients' and professional caregivers' ideas on when palliative home care should be initiated.

The research questions for this study were:

1. How did advanced cancer patients and their family caregivers experience the introduction to an early palliative home care intervention?
2. What were patients' and professional caregivers' (GPs and oncologists) ideas on when palliative home care should be initiated after participation in the EPHECT intervention?
3. Did participating in an early palliative care intervention have an influence on the perceptions of patients, family caregivers and professional caregivers on the content and purpose of early palliative home care?

METHOD

Study design

A mixed-methods phase II pre-post study was designed following the guidance of the Medical Research Council for the development and evaluation of complex interventions[21,22]. The full protocol of the EPHECT intervention has been published[20]. To assess feasibility and acceptability of the intervention components, interviews were conducted with patients, family caregivers, GPs and oncologists and a focus group with the PHC team after the intervention period.

Setting and participants

The EPHECT intervention was implemented in the home of the participating advanced cancer patients in the Brussels region. Oncologists recruited patients with advanced cancer from the Medical Oncology departments of a University hospital and a regional hospital. All already treated and all newly diagnosed patients in a non-curative setting were screened for their eligibility by five oncologists in the participating hospitals (see table 1 for inclusion criteria).

Table 1: inclusion and exclusion criteria

Inclusion	Exclusion
- Non-curative treatable solid cancer diagnosis - Life expectancy of 6 to 24 months (assessed by treating oncologist) - Identification as having palliative needs (assessed by treating oncologist) - Active anticancer treatment - 18 years or older - Patients with the ability to read and respond to questions in Dutch	- Hematological malignancy as primary diagnosis - Not housed in the Brussels region - No active anticancer treatment - No permission of the GP - More than one palliative care consultation with palliative team in hospital before inclusion - Involved in another palliative care intervention study - Impaired cognition

At the request of the oncologists of the participating hospitals, the EPHECT intervention[20] was proposed to patients as a *supportive care* intervention instead of a palliative care intervention. The oncologists felt more comfortable supporting an intervention focusing on supportive care.

After oncologists screened patients for eligibility, the data nurse introduced the EPHECT intervention to all eligible patients and asked whether they were willing to participate. When patients agreed to participate and filled in an informed consent, the data nurse contacted their GPs to ask permission to initiate palliative home care.

Data collection

At the end of the EPHECT intervention period, patients and informal caregivers were approached in person by the data nurse or by telephone for participation in an interview. All patients alive at the end of the study period and able to respond to questions in an interview, were approached for participation. All involved oncologists and GPs were also asked to be interviewed. If the data nurse had tried to contact the GP three times without response, then the GP was excluded. If patients identified a family caregiver to join in the interview, they were interviewed as a dyad. A topic guide for the interviews, consisting of open questions and a set of prompts, was developed by a member of the research team (ND) and reviewed within a multidisciplinary team of researchers (TS, ADV, KP, LL and LD). Interviewers were a member of the research team (ND) and a data manager.

Data analysis

All interviews were audio-recorded, transcribed verbatim and analyzed by a junior and a senior researcher (ND and TS). Following an inductive approach, the constant comparative method was used to compare fragments within and between interview[23,24]. Analyses started after the first interview and during the process of data collection. We started with a code tree and refined it based on the input of the research team. Thematic saturation was determined by consensus when no new themes in relation to the research questions emerged in the last interview. A final thematic framework was agreed and quotes from the interviews and focus group were selected, translated and approved by the research team to illustrate the results. Qualitative data analysis software (NVivo 12) was used.

Ethics

The Ethics Committees of the University Hospital and of the regional hospital approved the study protocol. All patients and informal caregivers provided written informed consent, as well as all involved GPs.

RESULTS

Of the 20 patients being alive at the end of the intervention period, 16 were approached and consented for the qualitative study of which 11 identified a family caregiver to join the interview. Reasons for not approaching were that 2 dropped out during the intervention due to personal reasons and 2 patients were too sick to respond to questions in an interview. Characteristics of the interviewed patients can be found in table 2. All 5 oncologists took part in an interview and also 6 of 30 GPs agreed on being interviewed. For GPs, the main reasons for not participating were a lack of time or difficulties experienced by the data nurse with approaching them. Examples of these difficulties are that the data nurse sometimes could only reach the office manager without being transferred to the GP and sometimes, the data nurse was already in the waiting room but could not meet the GP due to a lack of time or an acute home visit.

Table 2: Patient characteristics (n = 16)

	N	%
Age		
18-65	9	56%
>65	7	44%
Gender		
Male	8	50%
Female	8	50%
Hospital		
University hospital	7	44%
General hospital	9	56%
Primary caregiver in interview		
Yes	11	69%
No	5	31%
Primary cancer diagnosis		
Digestive	5	31%
Breast cancer triple negative	4	25%
Lung	2	12,5%
Gynecological	2	12,5%
Sarcomas	1	6,3%
Head-neck	1	6,3%
Prostate	1	6,3%

1. <u>How did advanced cancer patients and their family caregivers experience the introduction to an early palliative home care intervention?</u>

Most patients reported that being approached by the data manager to participate in the EPHECT intervention was confronting.

> *"It is confronting at the beginning, to hear that you are part of 'that' category. You know that deep inside, but you don't want to know it." (f, 60y, university hospital)*

> *"The confrontation of the fact that my name was given to you (the researcher) by the oncologist, that was the hardest part." (m, 65y, university hospital)*

Patients were shocked that they were eligible for palliative care because many of them perceived palliative care as terminal care, and they felt that they were not terminally ill. Some patients were anxious that this meant that they were sicker than they thought and would die within the next days or weeks. Furthermore, not all patients knew they had an incurable disease leading to an even more shocking effect. This also made some patients suspicious about whether their treating doctors had told them the truth about their diagnosis or prognosis.

> *"That was difficult for her, wondering if the end was that close." (family caregiver of female patient, 75y, general hospital)*

> *"Why now? Does my doctor know more than I know? Is there something he doesn't want to tell?" (m, 63y, general hospital)*

Despite having shocked and skeptical emotions, most patients acknowledged the potential value of a team that would focus on their quality of life and comfort. Stressing that the intervention had nothing to do with an expected short survival and emphasizing that the team would focus on comfort and quality of life was important for patients in initially accepting the intervention.

> *"He (the data manager) failed by accidentally using the word 'palliative' because I am not palliative. But then he told me that the intervention aimed to increase the well-being of cancer patients, and that can only be a positive evolution." (f, 75y, university hospital)*

Influence of previous experiences with palliative care on patients' initial reactions being introduced to early palliative home care

Almost all patients knew loved ones or friends who had received palliative care and these experiences had an influence on how people reacted to being introduced to early palliative home care. Most of them linked palliative care to situations in which friends or family members had died within days or weeks, often on a palliative care unit, leading to the assumption that palliative care was only given in the last phase of life.

> *"Being palliative is the end. His grandmother is dying, so she is in the palliative phase. I am better than that, I am not palliative." (m, 65y, university hospital)*

> *"We have visited friends on the palliative care unit and at that point you realize: once you are here, you will never come out and you will soon die." (f, 60y, university hospital)*

Some patients but especially the GPs had witnessed positive experiences with a palliative care team, resulting in being motivated and positive towards the EPHECT intervention.

> *"That PHC team has done lots of things for my neighbor. Unfortunately, they were introduced far too late and I believe that starting earlier will lead to even more beneficial effects." (f, 42y, general hospital)*

> *"I know the team very well, we sometimes work closely together. Their support can be very enriching for general practitioners." (GP1, m)*

2. When should early palliative home care be initiated?

We asked patients and family caregivers if the PHC team came at the right moment in their disease trajectory. Some of them answered that it depended more on the individual patient than on looking for the right moment in the disease trajectory. However, most of the patients said that if they had known earlier in their disease trajectory that it was possible to consult the PHC team, they probably would have done this.

We also asked the oncologists and GPs to reflect on who would be eligible for early palliative care. Surprisingly, all 5 oncologists had the opinion that palliative care should be introduced to all advanced cancer patients from metastatic diagnosis on. Not for intensive therapy in the beginning, but to introduce themselves and to let patients know that they exist if they would need them. Furthermore, they reported that it was easier to estimate a life expectancy of 6 months than a life expectancy of 24 months. Especially with the continuously developing anticancer therapies it becomes more difficult to predict someone's disease trajectory.

> *"I think it's a good idea. From metastases palliative home care can be introduced. The contacts will not be intensive at the beginning of the trajectory, but it can be helpful that patients know whom they can contact if needed." (female oncologist, university hospital)*

The interviewed GPs agreed on introducing the PHC team early in the disease trajectory but some were concerned about the possibility of 'overshooting' the patient too soon with sensitive topics and discussions about 'what if" by systematically bringing up a PHC team early in their trajectory.

> *"You have to be careful in bringing up palliative care to patients who are in a good condition. It depends on the person I think, but some of them will not accept it that early." (GP2, f)*

According to professional caregivers as well as to the patients and family caregivers, the introduction of specialized palliative care should be done when a patient is diagnosed with an advanced cancer disease, to build up a relationship of trust. Furthermore, some GPs and some patients said that the needs and wishes of patients had to be taken into account in deciding the intensity of contacts with the nurse of the PHC team.

3. Perceptions on the content and purpose of early palliative home care

Regardless of the direct negative reaction on early palliative home care mentioned above, during and after having taking part in the EPHECT intervention, most patients became more positive about the concept of palliative care; only one patient remained skeptical and reported that participating in the EPHECT intervention had no added value for him or his partner. Even though patients had felt shocking and negative emotions at the moment of introduction, almost all patients reported positive feelings about the visits of the PHC team.

> *"We are glad and thankful that we have participated in this study and that B (the palliative care nurse) can still visit us. At the end we can say: we would immediately agree on participating again." (f, 75y, general hospital)*

Nevertheless, some patients still thought they were not palliative and that the intervention could potentially be beneficial for them at a later stage, but not this early in their disease trajectory.

> *"If I have to be honest when looking back at the last 6 months, I don't think I need them right now. They want to give me a new anticancer therapy which means that I will live at least 3 more months, otherwise they would not propose it to me." (f, 75y, university hospital)*

However, the majority of patients reported that being part of the EPHECT intervention made them slowly realize that receiving palliative care does not necessarily mean a short survival time of a few weeks or months and that they actually belonged to patients eligible for receiving this sort of care. Necessary for this change in mindset was that patients accepted that their disease was incurable. Clear communication about their diagnosis and prognosis was herein crucial and we learn from the interviews that it was often an accomplishment of the nurses of the PHC team to increase the disease-insight of patients and to improve coping with their disease.

Also, most patients reported that they needed some time to get used to the idea of being supported by a PHC team. Once they began to accept themselves as a palliative patient, the PHC team helped in having thoughts and conversations about 'what if' and the impending death.

> *"She (the palliative care nurse) slowly prepared us. She was always honest and answered every question. She let us know in a subtle and acceptable way that he was dying. The word 'palliative' was not brought up in the first visits, but right now we know that we were in that situation the whole time."* (m, 64y, general hospital)

> *"It was confronting at the beginning, but now I think: it's true, my disease cannot be cured, I'm palliative." (f, 60y, university hospital)*

Although most patients experienced positive emotions about EPHECT, negative reactions on the term 'palliative' did not disappear after participating in the intervention. Most patients and family caregivers said that they still associated palliative care with terminal care, and therefore advised to rename palliative care as supportive care. According to most patients 'supportive care' had a more positive connotation compared to 'palliative care'. It refers to a period where some modifications are possible to live in optimal comfort and quality and where the focus still lies on being alive and not only on the dying process.

> *"Palliative care is future, but we are still far away from that moment." (f, 75y, general hospital)*

> *"Supportive care literally means being supported in your trajectory, palliative care means the end." (f, 60y, university hospital)*

Even though most patients acknowledged the value of early palliative care and the benefits of the EPHECT intervention, they said that they still associated the term palliative care with dying and that for this reason they and their friends and family still experienced feelings of fear and suspicion when hearing the term 'palliative'.

> *"For my generation palliative care means that you are in the last six weeks before…" (f, 75y, university hospital)*

> *"It's the same word as when you are at the palliative care unit and we all know that you are going to die once you arrive there." (m, 75y, general hospital)*

Except for one oncologist, all interviewed oncologists and GPs had the opinion that palliative care is still too confronting and still bears negative connotations for patients. Some of them said that changing the term to supportive care possibly would increase their willingness and readiness to refer patients to a specialized palliative care team. However, some were concerned that the alternative term would also eventually lead to negative attitudes and said that more should be done to rectify existing misconceptions and create awareness about palliative care in society.

DISCUSSION

Main findings

Most participants had negative and skeptical emotions when first asked to participate in the intervention. However, during the intervention and after having participated in the intervention patients became more positive about the meaning and content of palliative care. Despite their positive experiences with palliative care, patients remained skeptical and uncomfortable with the term ‘palliative’ because they kept associating the word with dying. According to oncologists, calling palliative care supportive care could remove a barrier for them to talk to patients about palliative care and for patients to accept it. Further, professional caregivers as well as patients and family caregivers found it appropriate to introduce palliative care services from diagnosis of advanced cancer on. Introductory visits at the time of diagnosis are valuable to establish a relationship between the palliative home care team and the patient and family caregiver.

Interpretation of the main findings

Experiencing negative and skeptical emotions when being asked to participate in a palliative care intervention confirms results of previous studies[25,26]. However, during the intervention and after having participated in the intervention patients became more positive about the content of palliative care[27]. Most of them reported that the visits of the PHC team felt comfortable and made them slowly realize that they had an incurable disease and were eligible for receiving palliative care. This might be a result of the fact that the nurse of the PHC team focused in the first visits on illness understanding and rapport building[28–30]. Furthermore, stressing that the intervention had nothing to do with an expected short survival and emphasizing that the team would focus on comfort and quality of life was important for patients in initially accepting the intervention.

Strikingly, although reporting overall positive feelings about the EPHECT intervention, most patients still felt uncomfortable when hearing the term ‘palliative’. Especially when they had to explain to family or friends what the PHC team did, the link with palliative care was too frightening and made them think that they would die very soon. These results are similar to reactions of patients after having participated in other palliative care interventions[27,31,32].

Several studies have suggested to rename palliative care to supportive care because results show that renaming it to supportive care leads to earlier and more referrals, more positive attitudes of oncologists to refer patients to specialized palliative care, and patients also prefer supportive care instead of palliative care[27,33–35]. When proposing this intervention to oncologists, some of them were skeptical and only wanted to participate if the intervention could be introduced as a supportive care intervention. By renaming it, the recruitment of patients went fluently and all oncologists were positive about the content of the EPHECT intervention.

When asking oncologists about the ideal time of referring patients to palliative home care, they reported that it was difficult to estimate a life expectancy of more than 6 months. This was also demonstrated in previous research showing that it can be difficult for oncologists to estimate survival and that they often have the tendency to be overly optimistic in estimating life expectancy[36–38]. Also, by giving oncologists prognosis-based criteria to select patients for eligibility, it might be that they purposefully involved especially patients with a limited prognosis of 6 months in the EPHECT intervention as 41% of the included patients had died before the end of the study period. Oncologists might have felt resistance to introduce the study to patients with a longer survival because they fear to deprive the hope of those patients, a barrier reported in several previous studies[12,26,39–43].

Overall, all oncologists and most GPs advised to introduce palliative care from diagnosis of advanced cancer. Not to give intensive support, but to have some introductory visits. Patients and family caregivers felt more that it depended more on how such care was introduced than on which point in the disease trajectory, which is in accordance to previous studies searching for the 'right timing' of palliative care[27,32].

Lessons learnt for professional caregivers, researchers and policy makers to enroll advanced cancer patients early into palliative home care

Renaming palliative care to supportive care could overcome a barrier for oncologists to talk to patients about end of life which confirms previous studies[33–35]. However, as our results show, some patients participating in the EPHECT intervention did not know that they had an incurable disease or they did not hear it when it was told leading to be shocked when introduced to early palliative home care. This advocates the need for clear communication between oncologists and patients about prognosis and diagnosis before early palliative care can be initiated[27,44].

For creating more awareness about the meaning of palliative care, more effort is thus needed than just overthinking if palliative care needs a renaming. Positive communication about and positive experiences with early integrated palliative care should be shared by professional caregivers and in the society[45]. As long as palliative care is seen as an option only delivered when life-prolonging treatments are no longer an option, the stigma will persist[44].

Furthermore, palliative care needs to be seen as part of standard care for advanced cancer patients, available to all patients and integrated in oncology treatment[27]. This is in accordance with the reflections of patients, family caregivers and professional caregivers who participated in the intervention on the ideal time of referral to palliative care. Importantly, not all patients felt the need to be intensively supported by the PHC team at that moment in their disease trajectory. Therefore, oncologists have to communicate the existence of specialized palliative care teams to patients and some introductory visits by the teams are recommended early in the trajectory. However, as palliative care needs can fluctuate over time, primary and secondary professional caregivers should regularly assess those needs in order to search for the 'right time' to intensify the support of the PHC team.

Strengths and limitations of this study

Of the 20 patients alive at the end of the intervention period, we succeeded on including 80% of the patients in a feasibility interview. 11 patients included a family caregiver and patients and family caregivers were together interviewed as a dyad, making social interaction and depth in the narratives possible[46]. However, we only managed to include 6 of 30 GPs in an interview which limits the generalizability of those results.

Conclusions

It is possible but challenging to initiate early palliative home care to patients and family caregivers. Renaming palliative care to supportive care might reduce barriers for professional caregivers to introduce early palliative care to patients. However, more effort is needed to establish changes in attitudes towards palliative care. First, the awareness of patients, professional caregivers and the society about the added value of early palliative care needs to be increased. Second, clear communication about diagnosis and prognosis is a first step in creating opportunities to introduce early palliative care to patients. Stressing that being eligible for early palliative care does not mean that they will die within weeks or months is important for patients' acceptance of being supported by a palliative home care team early in their disease trajectory. Therefore, it is recommended to introduce early palliative home care from diagnosis of advanced cancer on to build up a relationship and to make palliative care part of standard care for patients with advanced cancer.

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Part IV: General discussion and conclusions

Chapter 7

General discussion and conclusions

In this part, the main findings of the studies presented in this thesis will be shortly summarized, and the methods used will be discussed on their strengths and limitations. Furthermore, the main findings will be discussed in the light of current challenges and state of affairs in palliative care research. Finally, recommendations are made for future research, policy and practice.

7.1. Summary of the main findings

In **chapter 2** we discussed the **differences between early and late involvement of palliative home care into oncology care** as perceived by palliative home care (PHC) teams. The PHC teams experienced that being involved earlier in an oncological disease trajectory is different from being involved late in six overarching themes: 1) reasons for initiation, 2) planning of care process, 3) different mindset: focus on future goals versus problems, 4) opportunity to provide holistic care, 5) empowerment of patients, and 6) empowerment of professional caregivers involved in the home-care context with coordination of care process. Overall, a shift from a medical approach (late involvement) to a more holistic approach (early involvement) is the most noticeable difference. Being involved earlier also results in a more structured follow-up of the patient and in empowering the patient to take part in the decision-making process. Early involvement creates the need for transmural collaboration in the care of the patient, making the PHC teams responsible for taking on more supporting and coordinating tasks.

We studied **barriers for the early integration of palliative home care into oncology care** in **chapter 3**. Analyses of focus groups with members of PHC teams showed that most reported barriers confirmed those found in previous studies, such as the concern that there will be a lack of available financial resources to ensure the provision of optimal integrated palliative care and the existing societal perception of palliative care as terminal care resulting in possible negative attitudes of patients, family caregivers and professional caregivers towards early involvement of palliative care. Oncologists' lack of knowledge about the content and role of palliative care, according to the PHC teams, was also confirmed. Furthermore, nurses of the PHC teams said that they lacked important information on oncological diagnoses and therapies necessary to provide optimal concurrent palliative care. A specific barrier for the home context is the lack of central coordination of care and a lack of clear interdisciplinary communication, which hampers continuity of care.

Following the steps of the Medical Research Council (MRC) Framework for developing and evaluating complex interventions, we **developed** in **chapter 4 the Early Palliative Home Care Embedded in Cancer Treatment (EPHECT) intervention** to support the early integration of palliative home care into oncology care. Phase 0 consisted of a combination of a literature study on existing interventions focusing on early integration of palliative care in oncology care and a focus group study with PHC teams. In the literature study, we identified three key intervention components: 1) regular visits of the PHC team with the patient, 2) semi-structured consultations with a focus on both symptom management and psychosocial issues, and 3) education for involved health care professionals. Based on the results of the focus groups, the key components were adapted and supplemented for the healthcare context in Flanders, Belgium. In Phase 1, we developed the EPHECT intervention consisting of the following key components: 1) training sessions for the involved professional caregivers, 2) the general practitioner as coordinator of care, 3) regular and tailored home consultations by the palliative home care team, 4) the use of a semi-structured conversation guide to facilitate consultations, and 5) interprofessional and transmural collaboration.

In **chapter 5**, we described the **results of the phase 2 pre-post study** to investigate if the EPHECT intervention was feasible and acceptable for patients, family caregivers and professional caregivers and if results indicated that the intervention could have positive effects on quality of life, mood and satisfaction of care. This study shows that early integration of palliative home care into oncology care is feasible and acceptable for the most part by patients, family caregivers and professional caregivers. By only making small adjustments to current practice – being involved earlier and structuring the home visits, PHC teams are able to deliver early palliative care to advanced cancer patients. Results showed no decrease nor increase in patients' and family caregivers' quality of life, mood and satisfaction of care over time but patients and family caregivers did perceive positive effects on these outcomes. This phase 2 pre-post study further provides essential information on how the EPHECT intervention can be optimized before testing its effectiveness in a large-scale phase 3 RCT. The exploratory study showed that too little attention was given to the coping of some family caregivers with the disease of the patient. Furthermore, interviews with participants showed that systematic monthly consultations were only necessary in the beginning of the palliative care trajectory to build a relationship and rapport. The optimal frequency and structure of the home visits thus need to be reconsidered. Lastly, telephone-based contact seemed insufficient to support interprofessional collaboration. To strive for optimized integrated palliative care, professional caregivers from different disciplines and settings have to be gathered together to discuss future care goals.

We explored in **Chapter 6** the **experiences of patients, family caregivers and professional caregivers who participated in the EPHECT intervention. We investigated patients' and caregivers' experiences with** being introducing to the early palliative home care intervention and we explored their ideas on when early palliative care should ideally be initiated. Most participants had negative and skeptical emotions when first asked to participate in the intervention. However, during the intervention and after having participated in the intervention patients became more positive about the meaning and content of palliative care. However, despite their positive experiences with palliative care, they remained skeptical and uncomfortable with the term 'palliative' because they kept associating the word with dying. According to oncologists, calling palliative care supportive care could remove a barrier for them to talk to patients about palliative care and for patients to accept it. Further, professional caregivers as well as patients and family caregivers found it appropriate to introduce palliative care services from diagnosis of advanced cancer on. Introductory visits at the time of diagnosis are valuable to establish a relationship between the PHC team and the patient and family caregiver. Routine symptom assessment by professional caregivers working in primary and secondary care is further needed to decide on when more intensive follow-up visits of the PHC team are needed later on in the disease trajectory. Finally, to be able to accept palliative care, patients need clear communication and information from their professional caregivers about their diagnosis and prognosis, on the added value of early palliative care and they need to be explained that the initiation of early palliative care does not mean they are imminently dying.

7.2. Methodological considerations, strengths and limitations

In this dissertation, we developed an intervention to support the early integration of palliative home care into oncology care and tested it in an exploratory study. We used the Medical Research Council (MRC) Framework as a guidance and more specifically we used phases 0-2.

7.2.1. Strengths and limitations of the methods used in phase 0-2

*In **Phase 0: preclinical phase** we used two methods: screening of the literature and focus groups with palliative home care teams.*

Screening of the literature

The literature on interventions to support the early integration of palliative care into oncology care is extensive and rapidly increasing. Hence, a focused screening of the studies and analysis of the results provides insights and evidence for a new intervention model of early palliative home care. The Medical Research Council (MRC) Framework advises to perform a systematic literature review to identify the relevant, existing evidence base. It might be a limitation of our development phase that we did not execute a *systematic* literature review to identify key components of early palliative care interventions. However, the interventions that met our inclusion criteria are the same as those described in a recent systematic literature review of key components of early palliative care for advanced cancer patients by Haun et al[1]. Furthermore, the research field on integrated palliative care is rapidly developing and in the last two years results of additional randomized controlled models of early integration of palliative care into oncology care have been published. However, these do not include any components that were not included in our intervention model.[2,3] Also, we decided to only include RCTs because they provide higher evidence than other research designs – e.g. pre post studies – and it was important to only identify the components that were proven to be effective.

Focus group study

Second, a qualitative research design was used to gain insight in the differences between early and late involvement of palliative home care and the effect of being involved earlier on the working procedures and skills of palliative home care nurses and to examine the barriers of implementing integration of early palliative home care into standard oncology treatment. We chose focus group discussions as the best approach to explore the perceptions and experiences of the palliative home care teams, given the flexible approach stimulating reflection, discussion and interaction between participants[4,5].

An advantage of using existing teams is that the members are used to work together and to discuss openly their working procedures, patients and topics which stimulates self-reflection[5,6]. We further considered that the multidisciplinary character of the teams would allow us to gain insight into topics from different perspectives (physicians, nurses, psychologists) and from different points of view. Despite the beneficial effects, this method also might mean that some participants felt resistance in reporting their thoughts or opinions because they might have hesitated to show their competencies and views in front of their colleagues. However, the results of the qualitative data show that almost all members participated actively in the focus groups and shared their opinions. A possible risk of using existing teams is that responses of the participants might have been affected by social desirability, but we estimate this effect as rather small due to similar results found when comparing the focus groups. In ***Phase 1*** *which is meant to make a coherent model of the determined components and to develop the intervention materials, we used semi-structured interviews and workshops with involved professional caregivers and stakeholders.*

Based on the results of phase 0, we developed a preliminary intervention model. During the modelling phase, we conducted semi-structured interviews with members of the involved PHC team and oncologists to refine the intervention model. We also held 4 stakeholder workshops with representatives of patient groups, family caregivers, professionals working in palliative and primary care and with policy makers. A strength of this participatory approach was that all stakeholder parties were involved in further improving the intervention model and in thinking about ways to facilitate the implementation[7].

*In **Phase 2** we tested the intervention model in a pre-post study on its feasibility, acceptability and preliminary effectiveness.*

Performing a phase 2 study is more cost-effective than immediately carrying out a large-scale phase 3 RCT because the intervention can be further refined based on results of this study before it is tested in a phase 3 trial. However, several limitations exist with regards to the design of the phase 2 study. First, we did not use a randomized controlled trial design and therefore had no control group, so we cannot say if scores on the primary and the secondary outcomes for intervention patients evolve in a positive or negative way compared with standard care. Second, because of the complex nature of the intervention, it is not possible to make conclusions about the effectiveness of individual components.

Overall limitations

The way we developed the EPHECT intervention has several limitations. First, we did not use an explicit and elaborate theory telling how and why the intervention should work in a certain context and which component of the model would have the greatest impact on the outcomes. Despite the fact that the MRC Framework advises a theory-driven approach, it does not guide researchers on how to use theory in the design and evaluation of complex interventions[8]. We searched for key components of existing interventions, however, we did not examine how those components were linked and which causal mechanisms could lead to positive effects on certain outcomes. A careful process evaluation could have given some indications of the working mechanisms of the intervention and the barriers and facilitators for implementation[9]. Second, an important limitation is that we only have involved the palliative home care teams in a systematic way in the development phase of this project. Exploring the perspectives and meanings of other professional caregivers who fulfill an important role in the intervention model such as the oncologist and especially the general practitioner in the development phase would have led to more robust fundaments for creating the intervention model. Also, we chose outcomes based on the findings of previous intervention studies in the context of early palliative care. We did not involve patients, family caregivers or professional caregivers such as the GP or the oncologist in the choice of the outcomes. For example, a Theory of Change (TOC) – a theory of how and why an initiative works which can be empirically tested by measuring indicators for every expected step on the hypothesized causal pathway to impact – uses the process of backwards outcome mapping together with stakeholders. This means that the development phase starts by defining the ultimate impact and long-term outcomes that are to be achieved. It is advised to involve patients and family caregivers in this process to identify outcomes that matter most to patients and their families.[8,10]

Complementing the study with a more explicit theory-driven approach and a thorough process evaluation could have improved the design and evaluation of our complex interventions, thereby increasing the likelihood that the intervention will be effective, sustainable and scalable[8,9,11].

Lastly, we did not manage to include more than 6 GPs in the evaluation phase of this project and also only 5 oncologists were included. Because the EPHECT intervention failed on improving transmural and interdisciplinary collaboration, the results of this project should be discussed with several groups of professional caregivers representing for example oncologists from different regions and hospitals and GPs from different regions.

7.3. Discussion of the findings

In the section below, the main findings of the conducted studies in this dissertation will be discussed in the light of current state of affairs within existing research on early palliative care.

7.3.1. Existing barriers for early palliative home care

In chapter 3, existing barriers were discussed for the early integration of palliative home care into oncology care as perceived by palliative home care (PHC) teams. Identified major barriers were the societal perception of palliative care as being terminal care, the lack of knowledge of patients about their diagnosis and prognosis and the discontinuity of care between the home and the hospital setting. An important future concern is the lack of financial resources to provide early palliative home care systematically to all advanced cancer patients.

Destigmatizing palliative care

In the perception of patients, family caregivers, and healthcare professionals, palliative care is still associated with terminal care, which was shown in the resistance of oncologists participating in the EPHECT intervention when asked to introduce the intervention as a palliative care intervention. They argued that patients would have negative reactions and would have the idea that they were going to die very soon. This is also found in previous research on barriers for introducing palliative care[12–16]. Furthermore, despite feeling positive about the intervention, patients and family caregivers participating in the EPHECT intervention acknowledged having negative and skeptical feelings about the term palliative care. Other studies found similar reactions of patients after participating in early palliative care interventions[17–19] (chapter 6).

Several researchers have suggested to rename palliative care to supportive care because results of studies show that renaming it to supportive care leads to earlier and more referrals, more positive attitudes of oncologists to refer patients to specialized palliative care, and patients also prefer supportive care instead of palliative care[19–22]. When proposing the intervention to oncologists, some of them were skeptical and only wanted to participate if the intervention could be introduced as a supportive care intervention. The recruitment of patients went fluently and all oncologists were positive about the content of the EPHECT intervention (chapter 5).

However, some of the patients that participated in the intervention did not know that they had an incurable disease and were shocked when the intervention was proposed to them (chapter 6). This confirms the lack of patients' accurate information about their diagnosis and prognosis as a major barrier for introducing palliative care early in a disease trajectory (chapter 3). During the intervention patients became more positive about the concept of palliative care because the consultations with the nurse of the PHC team made them realize and accept that their disease was incurable (chapter 5 & 6). This advocates for better communication between oncologists and patients about the incurable nature of the disease and the patient's prognosis[19,23].

Instead of only changing palliative care into supportive care, efforts are needed to destigmatize palliative care. Several interventions have proven beneficial effects of early palliative care into oncology on patient and family outcomes and the patients and family caregivers who participated in the EPHECT intervention also perceived positive effects[2,3,24–28]. The content of palliative care and the added value of introducing palliative care early in the disease trajectory need to be clearly explained to patients and to professional caregivers[29].

Breaking the walls between care settings

An important barrier for integrating palliative home care into oncology care is the discontinuity of care between care settings. Interdisciplinary collaboration has to be facilitated by creating guidelines on when communication between professional caregivers in different settings has to take place and by clearly defining the roles of the different professional caregivers involved in the care for a patient (chapter 3). We decided to use telephone-based contact in the EPHECT intervention as a communication mechanism because a shared web-based communication platform is not yet available and the participants of the focus groups mentioned that the majority of communication happens by telephone in current care (chapter 4). We aimed to create an intervention model in which the GP could take up his or her responsibility in being the coordinator of the care trajectory. In trying to structure the communication process, the GP was asked to contact the PHC team if relevant information from the hospital passed by, and to contact the oncologist if relevant information from the PHC team needed to be transferred to the hospital (chapter 4).

However, it turned out that the EPHECT intervention failed on improving interdisciplinary collaboration and transmural communication. Analyses of the logbooks of the PHC team show that for most patients, the GP was only contacted once by a nurse of the PHC team, to inform the GP that the support of the PHC team was initiated. Unfortunately, only for a few patients two-way contact between the GP and the PHC team was installed, mostly when the patient deteriorated and came in the terminal phase of life or when medication had to be adjusted. Furthermore, contact from the home setting to the hospital setting only happened seldomly (chapter 5).

Involving specialized palliative care into oncology care urges the need for integration and collaboration. Leutz defined integration as "the search to connect the health care system with other human service system to improve outcome (clinical, satisfaction and efficiency)". In the article he proposed three levels of integration: linkage, coordination, and full integration.[30] Based upon the definition of integration by Leutz, our intervention would be described as somewhere between 'linkage' and 'coordination'[30]. Linkage means that there is a basic understanding of the various professional skills between professional caregivers, but all disciplines work in parallel or in series. Communicating by telephone just to inform other professional caregivers could be seen as linkage. In the cases where two-way contact was installed, we could say that we reached the level of 'coordination', because those patients were cared for following a well-structured plan based on the patient's needs in a trajectory where the overall responsibility was given to and taken on by the GP.

It might seem naive to think that telephone-based contact would facilitate the collaboration between the home and the hospital setting. However, in the light of a feasibility study, our aim was to test if our intervention model was feasible in the current healthcare practice in Flanders without changing structures on policy level. Furthermore, previous interventions did not describe how collaboration between different disciplines was organized as a component. In fact, as we look into previously published interventions aiming to support integrated palliative care, a systematic review shows that of the seven included studies only one[24] advised to routinely involve palliative care teams on multidisciplinary tumor conferences and in only three of them[24,25,31] communication and collaboration between the palliative and the oncological service was established[32,33].

A recent Lancet Commission paper on integration of palliative care into oncology care states that a multidisciplinary team approach, with systematic collaboration among team members from different professions within and across levels of care, is needed to strive for optimized integrated palliative care and to meet the level of 'full integration'[34]. Based on our findings and recommendations on integrated palliative care, we acknowledge that our intervention model needs to be adapted to reach a higher level of integration. The development of multidisciplinary meetings bringing professional caregivers from different care settings together is needed to facilitate early referral to palliative home care and to establish continuity of care. Professional caregivers have to learn the roles of the other disciplines, job descriptions have to be clarified and clear agreements on when and how transmural communication has to be organized need to be made (chapter 3).

Lack of financial resources as a concern for the systematic provision of early palliative home care

Participants of the focus group study mentioned the lack of financial resources as a future concern if palliative home care should be integrated systematically earlier in advanced cancer trajectories (chapter 3). Cancer evolving more and more to a chronic disease will lead to more patients living longer with cancer which will possibly have an impact on the amount and duration of care trajectories done by the PHC team, especially if palliative home care is systematically involved early and monthly in the care trajectory of advanced cancer patients. Members of the PHC team participating in the EPHECT intervention evaluated the intervention model as feasible, but only if home visits were not required monthly for all patients. Otherwise it would not be feasible with the current practical and financial resources (chapter 5).

Patients in the EPHECT intervention were seen by nurses of the PHC team on average 4 times, which is less often than the recommended monthly visits (chapter 5). According to patients and professional caregivers, introductory visits of the PHC team were needed at the beginning of the trajectory for mutual learning and trust and to build rapport. Same results are found in previous studies examining the content of palliative care consultations[35–37]. Once the relationship was established, monthly visits were deemed not needed as long as the health status of the patient remained stable. Furthermore, some patients who participated in the EPHECT intervention believed in the added value of the early integration of the PHC team, but mentioned that they did not feel the current need to be intensively supported by the team.

A recent meta-analysis assessed the effect of specialist palliative care on quality of life (QOL) and additional outcomes in patients with advanced cancer[38]. They found that specialist palliative care was associated with a rather small effect on QOL. The authors state that the effect sizes are smaller than expected and that this might be the result of the care approach used in the interventions. All interventions provided a ‘specialist palliative care for all’ which means that all included patients were exposed to specialist palliative care, even those who did not have palliative care needs at that moment.[38]

As confirmed by this dissertation, with cancer becoming more and more a chronic illness with a longer survival rate, the model of providing 'specialist palliative care to all' might not be feasible for specialized palliative care teams with their current resources[39–42].

Gaertner et al. recommend an approach in which generalist palliative care for all and specialist palliative care for those who need it is combined[38]. In this approach, routine screening by GPs and oncologists for palliative care needs should be a trigger to identify those who need specialist palliative care.[38] This approach is in line with the Lancet Oncology Commission that states that primary, secondary and tertiary palliative care have to work together and that more research is needed on the provision of primary and secondary care combined with specialist tertiary palliative care[34].

An adaptation of this model of 'early specialized palliative home care for all' might be needed and is discussed later on in this dissertation.

7.3.2. Content and structure of early palliative care

The PHC teams identified a shift from a medical approach focusing on pain and symptom management to a more holistic approach covering medical, as well as psychosocial and existential aspects of care as the most noticeable difference between early and late palliative care (Chapter 2). In the EPHECT intervention (Chapter 4) we therefore developed a semi-structured conversation guide covering the core domains of the holistic approach of early palliative care, which was evaluated positively by the nurses of the PHC team after the intervention period (Chapter 5).

Analyses of the conversation guide showed that the first visits were mainly focused on illness understanding, rapport building and establishing a relationship of trust between the patient and family caregiver and the nurse of the PHC team. This finding is confirmed in previous research exploring the elements that define early palliative care visits[36,37,43]. Rapport building in the beginning of the trajectory is crucial to discuss preferences about future care and more sensitive topics later in the care trajectory[35,44]. Indeed, psychosocial issues such as coping with the illness and preferences for future care were also addressed in the EPHECT intervention as topics being discussed, but were more prevalent in later discussions (Chapter 5).

Importantly, our results of the analyses of the logbooks of the nurses of the PHC team who delivered the EPHECT intervention show that symptom management was prominent in the first discussions as well as in later discussions. This was also found in previous studies on early integrated palliative care[2,37]. These results might suggest that symptom management needs to be systematically addressed by conducting routine symptom assessment which is also suggested by the Commission paper[34]. Based on this symptom assessment, a personalized needs-based model of early palliative care can be provided.

Compared with being involved late mainly focusing on acute symptom management, early in the disease trajectory psychological and social issues are more common[2,35,36]. The nurses of the PHC team doubted in the beginning of the intervention period that they would be able to handle this. However, the nurses reported afterwards that experience in early palliative care trajectories increased their capacities and self-confidence in tackling these issues; and most patients and family caregivers reported that the involvement of a psychologist would not have been of added value compared to the support they had received from the PHC team. However, some of them mentioned that they expected a psychologist or psychiatrist instead of a nurse which shows the need for psychological support early in the disease trajectory for some patients. This also advocates for a systematic personalized needs assessment to refer properly and timely to the professional caregivers who are needed[34].

In conclusion, being involved earlier gives the opportunity to provide holistic care and to spend more time on other topics than symptom management alone, as is often the case when being involved late. Furthermore, specialized palliative care teams have to be involved earlier in the disease trajectory because this leaves more time and space to have a structured and gradual built-up during the home visits which is needed to discuss sensitive topics later on. By making only small adjustments to current practice – involving them earlier in cancer trajectories and structuring the built-up of the home visits – PHC teams are able to deliver early holistic palliative care to advanced cancer patients as defined by the WHO[45].

7.3.3. Should referral to palliative care be prognosis-based or needs-based?

Based on research[32,46] and on results of our focus group study, we used a combination of prognosis-based criteria and needs-based criteria to include patients in the EPHECT intervention. In our phase 2 study, oncologists had to estimate a life expectancy of 6 to 24 months as first inclusion criterium to screen patients for their eligibility[47]. After all, the oncologists only used this criterium to identify patients eligible for the EPHECT intervention. Needs-based criteria were seldomly taken into account in making their decision.

At the end of the 6-month intervention period, 41% of the included patients had died. All oncologists reported that it was difficult to predict a life expectancy of more than 6 months, so it might be that there was a selection bias of the oncologists in favor of patients with a shorter life expectancy. As confirmed by our results above, oncologists often struggle with correctly estimating patient's prognosis, they mostly have the tendency to be overly optimistic in estimating the period of survival[48–51].

To help oncologists in estimating accurate prognoses and survival time and in identifying patients eligible to receive palliative care, the surprise question ("Would you be surprised if this patient died within the next twelve months?") has been recommended as a helpful tool to identify patients for referral to specialized palliative care services[48,52]. Several studies have shown the feasibility of the surprise question and the accuracy in predicting prognosis[53–55]. In response to the struggling of oncologists in predicting prognoses, several prognostic tools have recently been developed specifically for advanced cancer patients[56,57]. However, the current knowledge is insufficient to make recommendations on the best and the most accurate prognostic tool for clinical use[34].

Prognostication is important to open up space for discussions about place of care, advance care planning and whether palliative chemotherapy should be continued in order to avoid aggressive treatment in the last days or weeks of life[34]. However, due to new anticancer treatments, patients will live longer with an advanced cancer diagnosis and cancer will evolve more and more to a chronic illness as it is already recognized by the WHO[58]. Also, prognostic tools like the surprise question still rely on the judgement of oncologists even though research has proven that oncologists have the tendency of overestimating predicted survival[48]. Furthermore, research shows that from the moment where people begin receiving life-prolonging treatments, and even earlier in the disease trajectory, unmet care needs in the domains of palliative care can be present[59,60]. Although evidence for the accuracy of prognostic tools, patients with a longer survival expectancy but with palliative care needs might miss the support of specialized palliative care services[55,56].

In chapter 6, we looked for the 'right time' of referring patients to palliative home care from the perspective of oncologists, GPs, patients and family caregivers. Overall, all oncologists and most GPs advised on introducing palliative care from diagnosis of advanced cancer. Not to give intensive support, but to have some introductory visits. Patients and family caregivers had the opinion that it depended more on how and by whom palliative care was introduced than on which point in the disease trajectory, which is in accordance to previous studies searching for the 'right time' of palliative care[18,19,39].

A needs-based approach to identify patients eligible for palliative care is thus needed. In a recent Delphi study, international palliative care experts reached consensus on 11 major criteria for outpatient palliative care referral for advanced cancer patients; 9 of the 11 major criteria were needs-based criteria[46]. However, professional caregivers often struggle with identifying palliative care needs[61]. A major barrier is that patients often do not initiate conversations about their needs and also professional caregivers are hesitant in starting these conversations[62–64].

Patient-reported outcome measures (PROMs) are described as “measurements of any aspect of a patient’s health status that come directly from the patient” and are shown to facilitate a systematic and comprehensive approach to assessing patients’ needs and to identify problems that are often undertreated and not addressed within routine practice[65]. As we see that palliative care needs can be present early in an advanced cancer disease trajectory[60], professional caregivers working in primary or secondary care have to be aware of these needs and have to be able to address these needs in order to facilitate referral to specialized palliative care services if needed. Psychosocial, existential and spiritual needs are often undertreated by oncologists[66–69] and the use of PROMs in consultations can be used to increase the patient-centeredness of care and can lead to improved patient-physician communication, improved wellbeing and an increase of the awareness of symptoms that are currently often not addressed[70–73].

7.3.4. Does integrating palliative home care early in oncology care have beneficial effects on the quality of life of patients and family caregivers?

Quality of life has been the primary outcome of previous published RCTs showing a positive effect of early integrated palliative care, because quality of life encompasses how an individual measures the ‘goodness’ of multiple aspects of their life. Health related quality of life (HRQoL) is defined as optimum levels of mental, physical, role and social functioning and should also include some assessment of satisfaction of care, outcome and take into account future prospects of care.[74,75] Quality of life is seen as a multidimensional concept of patients’ perceptions of their current state of mind and should therefore be measured with both objective and subjective tools[74]. Validated questionnaires should be combined with the perceived effects on quality of life examined with qualitative research.

Patients reported that the nurse of the PHC team had relieved their discomfort and optimized their symptom management by suggesting other medications to the GP or to the patient. Furthermore, some patients mentioned that the visits helped them in reflecting on their wishes and needs about future care and in communicating these wishes to the oncologist. Almost all patients were positive about the visits of the palliative care nurse and reported that the extra support felt comfortable and trusted leading to higher satisfaction of care. For the family caregivers, the intervention had the biggest impact on their feelings of safety, trust and control. The interviewed family caregivers felt safe because they knew who they could contact if needed.

Although we did not choose for a RCT design and hence missed a control group to reflect on the trends in scores on the EORTC QLQ-C30[76,77], HADS[78] and FAMCARE[79], the subjective perceptions of patients and family caregivers showed that the EPHECT intervention had beneficial effects on different domains mentioned in the definition of HRQoL leading to the assumption that the intervention increased the quality of life of patients and family caregivers.

Strikingly, the initial scores of family caregivers on anxiety were high at baseline and remained that high on 12, 18 and 24 weeks. Previous research on quality of life of family caregivers of advanced cancer patients show that family caregivers often experience feelings of anxiety during the disease trajectory of their beloved ones[80–82]. In the EPHECT intervention, some family caregivers had the feeling that the nurse of the PHC team was focused on the patient and had expected to be involved more and to have received more support.

Family caregivers are often defined as unpaid, informal providers of care who have a personal connection to the patient and provide – especially when patients want to be cared for at home – one or more physical, social, practical and emotional tasks[83]. By doing this, they play a vital role in providing palliative care. However, fulfilling these roles can lead to needs that might be undertreated or not addressed. Family caregivers are taking thus a unique dual position of being a caregiver and being someone who needs support[84].

Future interventions should therefore be more directed to the dyad of patients and family caregivers instead of focusing on the patient with advanced cancer and regarding the quality of life of family caregivers as an additional aim[85].

7.3.5. What do we learn from this dissertation for future research on early integration of specialized palliative (home) care?

In current practice, specialized palliative care is introduced late in the disease trajectory of patients, often to solve acute pain in the terminal phase. This leaves no time for those teams to support the GP in the coordination of care, to focus on other palliative care domains than only symptom management, and to make the bridge between healthcare providers across settings, which stimulates continuity of care. To involve specialized palliative home care earlier in the disease trajectory of advanced cancer patients, the EPHECT intervention was developed consisting of several key components.

This dissertation shows that the EPHECT intervention made it possible for palliative home care teams to be introduced to advanced patients early in their disease trajectory. Being involved earlier opened space to focus on several domains of palliative care instead of only focusing on symptom management. Whilst in current practice only 9% of the trajectories done by the PHC team last longer than 6 months, in the EPHECT intervention 60% of the patients were still alive after 180 days. However, oncologists reported after the intervention that they found it difficult to estimate a life expectancy which might be an explanation for the 40% of patients that died before 6 months.

Therefore, instead of searching for the 'right time' of referral, the palliative care team in the hospital and the PHC team should be mentioned by the oncologist and by nurses specialized in oncology care in the first consultations after receiving the diagnosis of advanced cancer. Those teams should then introduce themselves to patients and family caregivers by doing some visits to inform them and to establish a relationship of trust which lowers the barriers for patients and family caregivers to contact the teams if needed[86]. Palliative care should be seen as part of standard care for advanced cancer patients, an approach in which patients can make use of the teams whenever needed at any phases in the disease trajectory.

We hoped by introducing palliative home care earlier in the disease trajectory of advanced cancer patients that those teams could support GPs in their role as coordinator care and that they could make the bridge between disciplines and across settings. By developing the EPHECT intervention, we expected that GPs would be more involved in the care for those patients and that they would be able supported by the PHC teams to improve collaboration between the home setting and the hospital setting. However, the EPHECT intervention failed on the integration component.

In conclusion, this current intervention model is not sustainable enough to be tested in a large-scale Phase 3 RCT. The model of providing 'specialist palliative care to all' is not feasible for specialized palliative care teams with their current resources[39–42]. As mentioned in chapter 3, participants of the focus group study mentioned the lack of financial resources as a future concern. Interviews and the focus group with professional caregivers who had participated in the EPHECT intervention confirmed these findings and revealed that early involvement would be feasible if home visits were not required monthly for all patients. Furthermore, by focusing on specialized palliative care, the potential role of generalist palliative care is neglected in the EPHECT intervention and in previous intervention models on early palliative care.

To strive for a more sustainable model of early palliative care provision, professional caregivers in generalist palliative care should be strengthened first in assessing and identifying palliative care needs, in providing generalist palliative care and in referring patients to specialized palliative care if complex situations would occur. By making use of PROMs, routine symptom assessment should be done by the oncologist, GP or other professional caregivers providing generalist palliative care together with patients and family caregivers on their consultations to screen for and to treat palliative care needs. Once palliative care needs are becoming too complex, patients should be addressed to the specialized palliative care team so that their support for that patient can be increased and intensified. After stabilizing the situation, the support by the PHC team can be diminished and the nurses of the PHC team can support the oncologist and the GP in giving advice on symptom assessment and primary palliative care, as it is described in their current job description[87].

This model requires intense collaboration between the primary, secondary and tertiary providers of palliative care to provide integrated palliative care[34]. The development of shared electronic records seems to be essential to maintain continuity of care and information; as well as establishing multidisciplinary meetings bringing together the different disciplines and different care settings to discuss identified palliative care needs and future care[88]. Furthermore, educational strategies should focus on informing oncologists and GPs about palliative care, informing palliative care specialists about oncology; and mostly on teamwork and collaborating with other disciplines and other settings.

Future research on strengthening generalist palliative care and on improving transmural collaboration and referral between generalist and specialist palliative care should be done in close collaboration with patients, family caregivers and primary, secondary and tertiary palliative care providers. Only if those conditions are fulfilled – strengthening generalist palliative care and improving interdisciplinary and transmural collaboration -, a new intervention model on early integration of specialized palliative home care in oncology care can be developed and tested following the steps of the MRC framework.

7.3.6. Recommendations

Our findings suggest that more could be done in supporting the early integration of palliative home care into oncology care. Based on the studies in this thesis, important recommendations can be made for future research, policy makers and practice regarding the initiation and provision of early palliative care in oncology care.

Implications for research

Introducing palliative home care early in a disease trajectory seems to be feasible and acceptable to patients, family caregivers and professional caregivers. However, future research is needed to answer the questions that remain after this dissertation: What is the optimal structure and frequency of home visits done by the palliative home care team? What is the most achievable level of integration? How can disciplines of different settings be gathered together to have face-to-face discussions about the future care for a patient? What is the best model to introduce specialized palliative care to all patients from diagnosis of advanced cancer on?

The EPHECT intervention should be adapted to the suggested changes based on the findings in this dissertation and the adapted model should then be tasted in a large-scale phase 3 randomized controlled trial to evaluate it for its effectiveness.

Research shows that family caregivers benefit of early integrated palliative care, but the mechanisms that lead to desired outcomes are unknown. Future interventions should be directed more to the patient-family caregiver dyad instead of focusing on the patient. A new cross-national research project is just started and will evaluate the effectiveness and cost-effectiveness of 2 psychosocial and educational interventions focusing on the patient-family caregiver dyad for people with advanced cancer (DIAdIC). Furthermore, in our intervention, some family caregivers have the feeling not being involved enough in the care for their beloved one. The majority of patients prefers to be cared for at home and to die at home[89–91]. Family caregivers can play an important role in achieving this. In developing interventions also focusing on the family caregiver it will be important to keep the balance between seeing the family caregiver as someone who cares for his or her beloved one and seeing the family caregiver as someone who has care needs.

Implications for policy

We have shown that many barriers exist for integrating palliative care early in a disease trajectory, so we have to consider which actions need to be made to overcome those barriers.

Rebranding of palliative care

Policy makers need to be aware of the existing societal perception of PC as terminal care, which is often mentioned in research as one of the major barriers for the early integration of palliative care. Several studies including the results of the EPHECT intervention have shown that early integration of palliative care in oncology care has beneficial effects of the quality of life of patients and family caregivers[2,3,24–28]. These results have to be disseminated by policy makers in order to raise the awareness of the society about the added value of early palliative care. Furthermore, while the end-of-life topic is popular in several television series, the focus on end of life is too often restricted to the euthanasia practice of the dying process. We therefore advocate for involving palliative care teams in situations on television to make palliative care part of life. Also we advocate for an increase in death literacy which means that there is a shift from ‘talking about end of life’ to create a compassionate community with community engagement and social actions to become more death literate.

Education and training

Education for patients and clinicians is needed, specifically on the components of palliative care and what palliative care has to offer early in a disease trajectory. Previous research shows that students in medical schools and professional caregivers in clinical practice have little training in palliative care and that they are not always confident in situations that require palliative care consultation or referral[15,92–95]. We advocate for palliative care being a mandatory course in the curriculum of all medical and social disciplines. Furthermore, internships in palliative care settings can provide experience with palliative care and end-of-life care. Professional caregivers also need more training in having bad news conversations and in communicating to patients about diagnoses and prognoses, because patients often miss important information which prevents them from having informed discussions about their preferences for future care. This is linked to the need of increasing generalist palliative care next to specialist palliative care. Lastly, professional caregivers working in the home setting need more information about oncological diseases and treatments to provide optimal palliative care concurrent with oncology care.

Facilitating interprofessional collaboration

General practitioners do see the coordination of care as part of their job, but they admit that this is a demanding and time-consuming task[95]. Their central role might be facilitated by better structuring the interdisciplinary and transmural collaboration. A lack of clear task descriptions of specialised PC teams and not knowing whom to address for certain problems are seen as important barriers to interdisciplinary collaboration[15,95,96] and are confirmed in this dissertation. Policy makers have to think about ways to let different disciplines and teams interact with each other. Furthermore, a shared web-based communication platform is needed to facilitate communication and to guarantee continuity of care. Lastly, a new format for multidisciplinary meetings are needed because the multidisciplinary oncology consults (MOCs) will not work in a model of early integrated palliative care[97]. Patients, family caregivers, general practitioners and oncologists need to be gathered together and policy makers have to think about ways to facilitate this.

Resources

The systematic, early introduction of specialized palliative care teams in a disease trajectory will require additionally financial resources. Patients will live longer with cancer and this will lead to longer care trajectories and to more patients being referred to palliative home care teams.

Implications for practice

Providing holistic palliative care

Research has proven that care needs on the core domains of palliative care can be present early in the disease trajectory[60]. Being involved earlier creates the opportunity to provide holistic care as described in the WHO definition on palliative care[45]. Professional caregivers providing generalist palliative care have to be aware of the possible presence of not only pain, but also care needs on other domains such as psychological, social or spiritual.

Referring to specialized palliative care should rather be needs-based than prognosis-based

Most intervention studies on early integration of specialized palliative care into oncology care used time-based criteria to refer patients to specialized palliative care. However, because palliative care needs can be present at any stage in the disease trajectory[60], referral to specialized palliative care should be needs-based rather than prognosis-based. Systematic needs assessment is therefore crucial in determining the 'right time' for palliative care in a personal needs-based way. We advise to use patient-reported outcome measures (PROMs) to support professional caregivers from primary and secondary care in their consultations to identify, treat and address palliative care needs.

Systematic consultations of a specialized palliative care team from diagnosis on

Several studies have proven benefits of early palliative care for patients which is provided in a structured way as opposed to palliative care on demand. The major difference with late involvement of specialized palliative care is the opportunity when involved earlier to build a relationship and to have a gradual built-up in topics being discussed. This dissertation shows that it is important to organize palliative care consultations from diagnosis of advanced cancer on to give patients and family caregivers the opportunity to learn the palliative home care team and to build a relationship of trust. Once the relationship is established, organisation of home visits should be rather needs-based than routinely structured which seems to be a more feasible model than providing 'specialist palliative care for all'.

Attention to family caregivers

General consensus in the literature exists that patients as well as family caregivers react to cancer as a dyad and both express needs that can be answered by professional caregivers[85]. Clinicians should be aware of the presence and the needs of family caregivers and should focus on the patient-family caregiver dyad. Previous research shows that family caregivers of patients with advanced cancer often experience feelings of anxiety and other psychosocial distress during and after the disease trajectory of their beloved ones[80,84]. Furthermore, some family caregivers of the EPHECT intervention reported feelings of not being involved enough in the care for his or her partner. Professional caregivers should therefore be aware of the dual position of family caregivers of being someone caring for his or her partner and someone needing support for their own needs.

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Summaries

English summary

INTRODUCTION

The development of new possible anticancer treatments has increased exponentially during the last years, leading to patients living longer with an advanced cancer disease. Recently, cancer has been recognized as a chronic illness together with diabetes, cardiovascular diseases and chronic respiratory diseases.

Patients diagnosed with an advanced cancer typically experience emotional and existential distress, as well as physical symptoms that might have an important influence on their functioning and wellbeing. Several studies show that these symptoms can be present early in the disease trajectory and typically increase as death approaches.

Those psychological, social and existential needs are often undertreated by oncologists because they mainly focus on guiding patients in treatment decisions and on controlling disease progression. Due to the increasing chronic character of the disease, caring for cancer patients needs a new approach focusing on those unmet needs. Palliative care is a patient-centered approach that aims to achieve the best quality of life of patients and their family caregivers with a life-limiting disease and addresses a range of care dimensions including physical, social, psychological and existential issues. To mitigate the needs of advanced cancer patients that are often undertreated by oncologists, several guidelines recommend to initiate palliative care early – ideally concurrent with life-prolonging treatment – and to intensify gradually as death approaches. This concept where palliative care is provided concurrent with anticancer treatment has been referred as “early palliative care” or “early integrated palliative care” or “early integration of palliative care”.

Scientific evidence is increasing on the beneficial effects of this new approach wherein palliative care is initiated early in the disease trajectory concurrent with life-prolonging treatment. At the start of this dissertation, three important randomized controlled trials (RCTs) were published showing beneficial effects of early palliative care for advanced cancer patients. Recently, a Belgian study also showed beneficial effects on the quality of life of patients and family caregivers. The 4 RCTs formed the basis for the intervention model developed and tested in this dissertation.

Those trials were developed for patients cared for in the hospital or in the outpatient setting. However, research shows that the majority of people eligible for receiving palliative care prefers to be cared for at home and also want to die at home. Palliative home care teams provide specialized palliative care to patients and family caregivers at home. Those teams have an advisory and mentoring function to patients and family caregivers, but also to general practitioners and nurses caring for the patient at home, and offer their expertise in pain therapy, symptom control, palliative care and psychosocial support. Research shows that patients who received the support of such a palliative home care team had reduced symptom burden and an increased chance of dying at home. For these reasons, palliative home care teams might become more important in providing early palliative care.

Palliative home care in Flanders is organized by 15 regional teams with a minimum of two fulltime palliative care nurses, one palliative care physician for 4 hours a week and one part-time administrative employee.

An advantage of palliative home care teams is that they are more familiar with the home context of patients than palliative care professionals working in the hospital. They can therefore rapidly detect which support patients and family caregivers need to be cared for at home in optimal circumstances. Being involved earlier in the disease trajectory creates more time to focus on giving expert advice to primary caregivers in providing generalist palliative care and symptom control which might lead to less unnecessary treatments or hospitalizations.

However, integrating palliative home care early into oncology care also poses several challenges. First of all, it requires collaboration between the home and the hospital setting. Interdisciplinary collaboration might cause confusion about responsibilities and task descriptions of the different disciplines, especially because professional caregivers of the palliative home care team and the oncology team are often not familiar. Second, general practitioners are fulfilling an important role in the care for a patient and are seen as the central coordinator of care, however, research shows that the contact between patients and their general practitioner often weakens from the moment patient start an anticancer treatment in the hospital and contacts with the oncologist are installed.

According to several studies, more than 60% of the trajectories done by a palliative home care team last less than 30 days showing that there is a need to interventions facilitating the early integration of palliative home care into oncology care. However, it will be challenging to develop an intervention model in which general practitioners are able to fulfil their role as coordinator of care and in which transmural collaboration can be installed and facilitated.

STUDY OBJECTIVES

The overall objective of this dissertation is to develop and evaluate a new model of early integration of palliative home care in standard oncological treatment (hereafter called EPHECT intervention) in Flanders, Belgium, with the aim of improving the quality of life of and quality of care for patients with advanced cancer.

The objective can be divided into two scientific aims.

The first aim is the *development* of a model to integrate palliative home care early in standard oncological treatment for patients with cancer in an advanced stage.

Specific objectives are:

1. To gather information on the current healthcare context by gaining insight into differences between early and late involvement of palliative home care and the effect on existing working procedures and skills as perceived by palliative home care teams,
2. To examine potential barriers for early palliative home care in standard oncology treatment in Flanders, Belgium as perceived by palliative home care teams,
3. To use these results to develop a new and potentially feasible, acceptable and effective integration model.

The second aim is to *implement and evaluate* the newly developed intervention model in a phase II study to prepare for a large phase III randomized controlled trial.

Specific objectives are:

4. To assess the feasibility and acceptability of the study procedures (e.g. recruitment, inclusion criteria),
5. To assess the feasibility and acceptability of the components of the EPHECT intervention, according to patients, family caregivers and healthcare professionals,
6. To explore preliminary effectiveness of the EPHECT intervention on the quality of life of patients and family caregivers and effects as perceived by patients, family caregivers and healthcare professionals,
7. To formulate recommendations for future care on when and how advanced cancer patients should be enrolled into palliative care.

METHODS

To reach the aims of this dissertation, the UK Medical Research Council (MRC) Framework for developing and evaluating complex interventions was used as a methodological guidance. The framework helps researchers to identify the core components of interventions – e.g. essential features that define an effective intervention and produce desired outcomes – and allows a degree of flexibility in tailoring of the intervention. The MRC Framework distinguishes between four different phases: 1) intervention development, 2) feasibility and piloting of the intervention model, 3) evaluation and 4) implementation. The chapters in this dissertation describe a Phase 0-II study including the development, modelling and piloting of a complex intervention to support the early integration of palliative home care in oncology care.

Phase 0: identifying the key components

We used two methods to obtain data and evidence for the development of the key components of the intervention, by gaining insight in evidence based practices in early palliative care research and in the healthcare context in which the intervention would be implemented.

3. <u>Literature search</u>

We performed a screening of the literature of existing and tested models of integration of palliative care into oncological care in different care settings and different countries. We limited our search to cluster-randomized controlled trials on integrated oncology care for people with advanced cancer and a prognosis of two years or less. We limited our search to studies that were published before the end of 2016, because the analyses of the literature search and the building of the intervention model started in 2017.

4. <u>Focus groups with PHC teams</u>

We conducted six focus groups with members of the PHC teams (n=51) to gain insight into differences between early and late involvement of PHC and into perceived barriers to early involvement. We also discussed a preliminary model for early integration based on the key components identified in the literature with the aim of reflecting on them and adapting them to the current working context of PHC in Flanders. As those teams have a coordinating role in organizing primary healthcare, they are ideally placed to provide contextual insights and essential information on how palliative care is structured and organized in the home setting and on how they work together with oncological services.

Phase 1: modelling of intervention and development of the intervention materials

Based on the results of phase 0, we developed a preliminary intervention model to support the early integration of palliative home care into oncology care. During the modelling phase, we conducted semi-structured interviews with members of a PHC team and oncologists and used their feedback on the preliminary model. We also held 4 stakeholder workshops with representing patient groups, family caregivers, professionals working in palliative and primary care and with policy makers. The aim of this participatory approach was to explore the experiences of people with a serious illness and those surrounding them, and to brainstorm about how to further improve the intervention model[64]. The model was further refined at monthly meetings with the multidisciplinary research team consisting of psychologists, sociologists and a medical oncologist.

Phase 2: evaluating the newly developed intervention in a pre-post phase 2 trial on feasibility, acceptability and preliminary effectiveness

The primary objective was to assess the feasibility and acceptability of the EPHECT intervention as perceived by participating patients, family caregivers, general practitioners, oncologists and the palliative home care team. The feasibility and acceptability of the EPHECT intervention was evaluated in interviews with participating patients, family caregivers, GPs and oncologists who participated in the EPHECT intervention and in a focus group with the participating PHC team; and by registering the number of visits done by the PHC team, by analyzing the content of the conversations and the time spent on different topics, by registering and analyzing the amount of and reasons for interprofessional contact which was all gathered in the logbooks of the researcher, data nurse and the PHC team and in the electronic patient files.

The secondary objective was evaluating the preliminary effectiveness of the EPHECT intervention which was assessed by questionnaires focusing on quality of life, mood and satisfaction with care filled in by patients and family caregivers at baseline, and after 12, 18 and 24 weeks.

SUMMARY OF THE MAIN FINDINGS

In **chapter 2** we discussed the **differences between early and late involvement of palliative home care into oncology care** as perceived by palliative home care (PHC) teams. The PHC teams experienced that being involved earlier in an oncological disease trajectory is different from being involved late in six overarching themes: 1) reasons for initiation, 2) planning of care process, 3) different mindset: focus on future goals versus problems, 4) opportunity to provide holistic care, 5) empowerment of patients, and 6) empowerment of professional caregivers involved in the home-care context with coordination of care process. Overall, a shift from a medical approach (late involvement) to a more holistic approach (early involvement) is the most noticeable difference. Being involved earlier also results in a more structured follow-up of the patient and in empowering the patient to take part in the decision-making process. Early involvement creates the need for transmural collaboration in the care of the patient, making the PHC teams responsible for taking on more supporting and coordinating tasks.

We studied **barriers for the early integration of palliative home care into oncology care** in **chapter 3**. Analyses of focus groups with members of PHC teams showed that most reported barriers confirmed those found in previous studies, such as the concern that there will be a lack of available financial resources to ensure the provision of optimal integrated palliative care and the existing societal perception of palliative care as terminal care resulting in possible negative attitudes of patients, family caregivers and professional caregivers towards early involvement of palliative care. Oncologists' lack of knowledge about the content and role of palliative care, according to the PHC teams, was also confirmed. Furthermore, nurses of the PHC teams said that they lacked important information on oncological diagnoses and therapies necessary to provide optimal concurrent palliative care. A specific barrier for the home context is the lack of central coordination of care and a lack of clear interdisciplinary communication, which hampers continuity of care.

Following the steps of the Medical Research Council (MRC) Framework for developing and evaluating complex interventions, we **developed** in **chapter 4 the Early Palliative Home Care Embedded in Cancer Treatment (EPHECT) intervention** to support the early integration of palliative home care into oncology care. Phase 0 consisted of a combination of a literature study on existing interventions focusing on early integration of palliative care in oncology care and a focus group study with PHC teams. In the literature study, we identified three key intervention components: 1) regular visits of the PHC team with the patient, 2) semi-structured consultations with a focus on both symptom management and psychosocial issues, and 3) education for involved health care professionals. Based on the results of the focus groups, the key components were adapted and supplemented for the healthcare context in Flanders, Belgium. In Phase 1, we developed the EPHECT intervention consisting of the following key components: 1) training sessions for the involved professional caregivers, 2) the general practitioner as coordinator of care, 3) regular and tailored home consultations by the palliative home care team, 4) the use of a semi-structured conversation guide to facilitate consultations, and 5) interprofessional and transmural collaboration.

In **chapter 5**, we described the **results of the phase 2 pre-post study** to investigate if the EPHECT intervention was feasible and acceptable for patients, family caregivers and professional caregivers and if results indicated that the intervention could have positive effects on quality of life, mood and satisfaction of care. This study shows that early integration of palliative home care into oncology care is feasible and acceptable for the most part by patients, family caregivers and professional caregivers. By only making small adjustments to current practice – being involved earlier and structuring the home visits, PHC teams are able to deliver early palliative care to advanced cancer patients. Results showed no decrease nor increase in patients' and family caregivers' quality of life, mood and satisfaction of care over time but patients and family caregivers did perceive positive effects on these outcomes. This phase 2 pre-post study further provides essential information on how the EPHECT intervention can be optimized before testing its effectiveness in a large-scale phase 3 RCT. The exploratory study showed that too little attention was given to the coping of some family caregivers with the disease of the patient. Furthermore, interviews with participants showed that systematic monthly consultations were only necessary in the beginning of the palliative care trajectory to build a relationship and rapport. The optimal frequency and structure of the home visits thus need to be reconsidered. Lastly, telephone-based contact seemed insufficient to support interprofessional collaboration. To strive for optimized integrated palliative care, professional caregivers from different disciplines and settings have to be gathered together to discuss future care goals.

We explored in **Chapter 6** the **experiences of patients, family caregivers and professional caregivers who participated in the EPHECT intervention. We investigated patients' and caregivers' experiences with** being introducing to the early palliative home care intervention and we explored their ideas on when early palliative care should ideally be initiated. Most participants had negative and skeptical emotions when first asked to participate in the intervention. However, during the intervention and after having participated in the intervention patients became more positive about the meaning and content of palliative care. However, despite their positive experiences with palliative care, they remained skeptical and uncomfortable with the term 'palliative' because they kept associating the word with dying. According to oncologists, calling palliative care supportive care could remove a barrier for them to talk to patients about palliative care and for patients to accept it. Further, professional caregivers as well as patients and family caregivers found it appropriate to introduce palliative care services from diagnosis of advanced cancer on. Introductory visits at the time of diagnosis are valuable to establish a relationship between the PHC team and the patient and family caregiver. Routine symptom assessment by professional caregivers working in primary and secondary care is further needed to decide on when more intensive follow-up visits of the PHC team are needed later on in the disease trajectory. Finally, to be able to accept palliative care, patients need clear communication and information from their professional caregivers about their diagnosis and prognosis, on the added value of early palliative care and they need to be explained that the initiation of early palliative care does not mean they are imminently dying.

DISCUSSION OF THE FINDINGS

Existing barriers for early palliative home care

In the perception of patients, family caregivers, and healthcare professionals, palliative care is still associated with terminal care. Even though the EPHECT intervention was evaluated positively, patients and family caregivers acknowledged having negative and skeptical feelings about the term palliative care. An important barrier to talk about early palliative care was and is the lack of accurate information of patients about their diagnosis and prognosis. During the EPHECT intervention, patients became more positive about the content of palliative care because the consultations with the nurse of the PHCT team made them realize and accept that their disease was incurable. This advocates for better communication between oncologists and patients about prognosis and the incurable nature of the disease. Furthermore, to change attitudes to palliative, efforts are needed to destigmatize palliative care. The content of palliative care and the added value of receiving it early in the disease trajectory need to be clearly explained to patients.

A second barrier is the discontinuity of care between care settings. In the EPHECT intervention telephone-based contact was used to facilitate communication between disciplines. However, it turned out that we failed on improving interdisciplinary collaboration. Based on our findings, we acknowledge that our intervention model needs to be adapted to optimize integrated palliative care. The development of multidisciplinary meetings bringing disciplines and care settings together is needed to facilitate early referral to palliative home care and to guarantee continuity of care.

Patients in the EPHECT intervention were seen by nurses of the PHC team on average 4 times, which is less often than the recommended monthly visits. However, according to patients and professional caregivers, introductory visits were needed in the beginning to build a relationship. After that, monthly visits were deemed not needed as long as the patient remained stable. PHC teams in the focus group study reported that they would lack financial resources if palliative home care would be available for all advanced cancer patients. Therefore, instead of providing specialist palliative care to all which might not be feasible with the current resources, we advocate for a model in which PHC teams are having introductory visits with patients but the follow-up will depend upon the needs and wishes of the patients and the family caregivers.

Content and structure of early palliative care

Analyses of the conversation guide showed that the first visits were mainly focused on illness understanding, rapport building and establishing a relationship of trust between the patient and family caregiver and the nurse of the PHC team. Rapport building in the beginning of the trajectory is crucial to discuss preferences about future care and more sensitive topics later in the care trajectory. In conclusion, being involved earlier gives the opportunity to provide holistic care and to spend more time on other topics than symptom management alone, as is often the case when being involved late. Furthermore, specialized palliative care teams have to be involved earlier in the disease trajectory because this leaves more time and space to have a structured and gradual built-up during the home visits which is needed to discuss sensitive topics later on. By making only small adjustments to current practice – involving them earlier in cancer trajectories and structuring the built-up of the home visits – PHC teams are able to deliver early holistic palliative care to advanced cancer patients as defined by the WHO.

Should referral to palliative care be prognosis-based or needs-based?

In our intervention, oncologists had to estimate a life expectancy of 6 to 24 months as first inclusion criterium to screen patients for their eligibility. However, they reported that it was difficult to predict a life expectancy of more than 6 months. As confirmed by these results, oncologists often struggle with correctly estimating patient's prognosis. Furthermore, due to new anticancer treatments, patients will live longer with an advanced cancer diagnosis and cancer will evolve more and more to a chronic illness. Also, research shows that from the moment where people begin receiving life-prolonging treatments, and even earlier in the disease trajectory, unmet care needs in the domains of palliative care can be present. All this advocates for a needs-based model to refer patients to early palliative care. As professional caregivers often struggle with identifying palliative care needs, tools are needed to support them in having conversations with patients about those needs. We therefore advise to use patient-reported outcome measures (PROMs) to facilitate these consultations.

Does integrating palliative home care early in oncology care have beneficial effects on the quality of life of patients and family caregivers?

The subjective perceptions of patients and family caregivers showed that the EPHECT intervention had beneficial effects on different domains mentioned in the definition of quality of life leading to the assumption that the intervention increased the quality of life of patients and family caregivers. Strikingly, anxiety scores of family caregivers were high during the intervention. Some of them also had the feeling that the nurse of the PHC team was mainly focused on the patient. Future interventions should therefore be more directed to the dyad of patients and family caregivers instead of focusing on the patient with advanced cancer and regarding the quality of life of family caregivers as an additional aim.

What do we learn from this dissertation for future research on early integration of specialized palliative (home) care?

This current intervention model is not sustainable enough to be tested in a large-scale Phase 3 RCT. The model of providing 'specialist palliative care to all' is not feasible for specialized palliative care teams with their current resources.

Palliative care should be seen as part of standard care for advanced cancer patients, an approach in which patients can make use of the teams whenever needed at any phases in the disease trajectory. Palliative care teams should introduce themselves to patients and family caregivers by doing some visits to inform them and to establish a relationship of trust which lowers the barriers for patients and family caregivers to contact the teams if needed.

Further, the provision of generalist palliative care should be expanded and strengthened. By making use of PROMs, routine symptom assessment should be done by the oncologist or by the GP on their consultations to screen for and to treat palliative care needs. Once palliative care needs are becoming too complex, patients should be addressed to the specialized palliative care team so that their support for that patient can be increased and intensified.

This model requires intense collaboration between the primary, secondary and tertiary providers of palliative care to provide integrated palliative care. The development of shared electronic records seems to be essential to maintain continuity of care and information; as well as establishing multidisciplinary meetings bringing together the different disciplines and different care settings to discuss identified palliative care needs and future care.

Suggestions for future research

Several research questions remain after this dissertation and are food for future research:

- What is the optimal structure and frequency of home visits by a palliative home care team?
- What is the most achievable level of integration and what is needed to reach this?
- What is the best model of introducing specialist palliative care to all patients with advanced cancer from diagnosis on?

Further, the EPHECT intervention needs to be adapted based on the findings of this dissertation before testing its effectiveness in a large scale phase 3 RCT.

Future interventions should focus on the family caregiver as being someone who provides care and someone who needs care.

Implications for policy

Increase the awareness of the value and content of early palliative care

Increase palliative care skills of professional caregivers

Facilitate interprofessional collaboration

Expand financial resources for specialized palliative care teams

Implications for practice

Provide holistic palliative care to patients from diagnosis of advanced cancer on

Referral to specialized palliative care should be needs-based instead of based on prognosis

Systematic consultations of a specialized palliative care team are recommended to build a relationship of trust with patient and family caregiver

More attention to the dual position of family caregivers as being someone who provides care and someone who needs support of professional caregivers

Nederlandstalige samenvatting

INLEIDING

De laatste jaren worden steeds meer nieuwe kankerbehandelingen ontwikkeld naast de klassieke chemotherapie, wat er voor zorgt dat patiënten met kanker langer leven. Recent is kanker dan ook erkend als een chronische ziekte, net zoals diabetes, hart- en vaataandoeningen en chronische ziekten van het ademhalingsstelsel.

Patiënten met een geavanceerde kanker hebben dikwijls emotionele en spirituele noden, alsook fysieke symptomen die een belangrijke invloed kunnen hebben op hun functioneren en welbevinden. Verschillende studies tonen aan dat deze symptomen al vroeg in het ziektetraject aanwezig kunnen zijn en vaak toenemen naarmate de dood dichterbij komt.

De genoemde spirituele, psychosociale en existentiële noden worden vaak onderbehandeld door oncologen die zich voornamelijk richten op het ondersteunen van patiënten in het maken van beslissingen en het onder controle houden van de ziekte. Door het steeds chronischer worden van kanker, is een nieuwe aanpak nodig die zich richt op deze noden. Palliatieve zorg wordt gezien als een patiëntgerichte zorg die verschillende domeinen wat betreft noden en inzet op het welbevinden van zowel patiënten als mantelzorgers. Om tegemoet te komen aan de noden die reeds vroeg in het ziektetraject aanwezig kunnen zijn, raden verschillende medische organisaties aan om palliatieve zorg vroeg in het traject op te starten – idealiter gelijktijdig met levensverlengende kankerbehandelingen – en gradueel intensiever te laten worden naarmate de dood dichterbij komt. Deze palliatieve zorg wordt ook wel “vroege palliatieve zorg” of “geïntegreerde palliatieve zorg” genoemd.

Er is steeds meer wetenschappelijke evidentie voor deze nieuwe benadering waarin palliatieve zorg vroeg in het ziektetraject wordt aangeboden naast levensverlengende kankerbehandelingen. Voor de start van dit doctoraat waren drie belangrijke interventies gepubliceerd die voordelen hebben getoond van vroege palliatieve zorg voor patiënten met kanker en deze interventies hebben de basis gevormd van dit doctoraat.

Deze drie studies zijn echter ontwikkeld voor patiënten die verzorgd werden in het ziekenhuis. Onderzoek toont echter aan dat de meerderheid van patiënten thuis wil verzorgd worden en ook thuis wil sterven. Palliatieve thuiszorgteams hebben een adviserende en ondersteunende functie naar patiënten en mantelzorgers, maar ook naar huisartsen en verpleegkundigen in de thuiszorg en bieden expertise in pijntherapie, symptoomcontrole, palliatieve zorg en psychosociale ondersteuning. Blijkt nu uit onderzoek dat patiënten die ondersteund worden door een palliatief thuiszorgteam minder symptoomlast hebben en meer kans hebben om thuis te sterven.

Palliatieve thuiszorg is in België georganiseerd door 15 teams bestaande uit minimum twee voltijdse palliatief verpleegkundigen en een palliatief arts, soms ondersteund door een psycholoog. Een voordeel van palliatieve thuiszorgteams ten opzichte van palliatieve teams in het ziekenhuis is dat zij dicht bij de patiënt staan in de thuisomgeving en dus ook snel kunnen signaleren wat patiënten en mantelzorgers nodig hebben om in optimale omstandigheden thuis verzorgd te worden en dus ook thuis te kunnen blijven. Wanneer ze vroeger bij een patiënten worden gebracht, hebben ze tijd om te focussen op het geven van advies aan huisartsen en thuisverpleegkundigen in het geven van algemene palliatieve zorg en symptoomcontrole wat onnodige behandelingen en hospitalisaties kan vermijden.

Maar palliatieve thuiszorg vroeger integreren in de oncologische zorg vereist samenwerking tussen verschillende settings. Dit kan een uitdaging vormen omdat de teams elkaar vaak niet kennen, het niet altijd duidelijk is wie welke taak moet vervullen. Voorts heeft de huisarts in dit model een centrale rol, maar uit onderzoek blijkt dat het contact tussen de patiënt en zijn huisarts vaak verwatert zolang de patiënt in behandeling is bij een oncoloog.

Onderzoek toont aan dat meer dan 60% van alle begeleidingen door een palliatief thuiszorgteam minder dan 30 dagen duren. Dit toont aan dat er een nood is aan interventies die de vroege opstart van palliatieve thuiszorg in de oncologische zorg ondersteunen. Het zal echter een uitdaging zijn om de huisarts in staat te stellen zijn centrale rol als zorgcoördinator op te nemen en om een manier te zoeken om samenwerking tussen de thuissetting en de ziekenhuissetting te faciliteren.

DOELSTELLINGEN VAN DIT DOCTORAAT

De algemene doelstelling van dit doctoraat is het ontwikkelen en evalueren van een nieuw model van vroege integratie van palliatieve thuiszorg in de oncologische zorg in België gedoeld op het verbeteren van de levenskwaliteit van en de kwaliteit van zorg voor patiënten met geavanceerde kanker; en kan opgedeeld worden in twee subdoelen.

Het eerste doel is het ontwikkelen van een model voor de vroege integratie van palliatieve thuiszorg in de standaard oncologische zorg voor patiënten met geavanceerde kanker. Specifieke doelstellingen zijn:

1. Een oplijsting maken van bestaande integratiemodellen in verschillende settings om te komen tot sleutelcomponenten
2. Informatie verzamelen over de huidige zorgcontext door inzichten te verwerven in verschillen tussen vroege en late inschakeling van palliatieve thuiszorg en het effect van vroeger inschakelen op werkprocedures en vaardigheden

3. In kaart brengen van de bestaande barrières om palliatieve thuiszorg vroeger te integreren in de standaard oncologische zorg in België
4. Bovenstaande resultaten om een nieuw en mogelijk haalbaar, aanvaardbaar en efficiënt model te ontwikkelen

Het tweede doel is om het nieuw ontwikkelde model te implementeren en te evalueren. Specifieke doelstellingen zijn:

5. Haalbaarheid en aanvaardbaarheid nagaan van de studieprocedures (vb. rekrutering, inclusiecriteria)
6. Haalbaarheid en aanvaardbaarheid van de componenten van de interventie nagaan, vanuit de perceptie van patiënten, mantelzorgers en professionele zorgverleners
7. Preliminaire effectiviteit nagaan van de interventie op levenskwaliteit van en kwaliteit van zorg voor patiënten en mantelzorgers
8. Aanbevelingen formuleren voor toekomstige zorg over wanneer en hoe kankerpatiënten moeten benaderd worden voor het krijgen van palliatieve zorg

METHODE

We gebruikten het UK Medical Research Council (MRC) Framework voor het ontwikkelen en evalueren van complexe interventie als methodologische richtlijn. Dit Framework helpt onderzoekers om sleutelcomponenten – i.e. essentiële onderdelen die leiden tot de gewenste uitkomsten – van interventies te onderscheiden en laat een zekere mate van flexibiliteit toe in het ontwerpen van de interventie. Vier fasen worden onderscheiden in het Framework: 1) interventieontwikkeling, 2) piloottesten van het model om haalbaarheid na te gaan, 3) evaluatie en 4) implementatie. In dit doctoraat werd een studie ontwikkeld die fasen 0-2 volgt van het Framework en omvat dus de ontwikkeling, het modelleren en het piloottesten van een complexe interventie om vroege integratie van palliatieve thuiszorg in de oncologische zorg te bevorderen.

Fase 0: identificeren van sleutelcomponenten

Ten eerste zochten we in de bestaande literatuur naar geteste en bewezen modellen van integratie van palliatieve zorg in de oncologische zorg in verschillende settings en verschillende landen. We includeerden enkel interventies die getest waren op hun effectiviteit voor verschillende uitkomsten en die positieve effecten toonden op primaire en/of secundaire uitkomstmaten. Als inclusiecriteria hanteerden we: gericht op kankerpatiënten met een prognose van twee jaar of minder, palliatieve zorg naast kankerbehandelingen, multidisciplinair georiënteerd. We beperkten onze zoektocht tot studies gepubliceerd voor het einde van 2016, omdat de analyses van het literatuuronderzoek en het opbouwen van het interventiemodel startte in 2017.

Voorts organiseerden we zes focusgroepen met bestaande palliatieve thuiszorgteams om inzicht te krijgen in de verschillen tussen vroeg en laat ingeschakeld worden in een ziektetraject en in bestaande barrières voor vroege inschakeling. We bediscussieerden ook een preliminair interventiemodel gebaseerd op de sleutelcomponenten uit het literatuuronderzoek met de bedoeling om deze aan te passen aan de huidige zorgcontext van palliatieve thuiszorg in Vlaanderen. We bevroegen alle 15 palliatieve thuiszorgteams in Vlaanderen en in de eerste ronde hadden zes teams geaccepteerd om deel te nemen aan het onderzoek.

Fase 1: modelleren van de interventie en ontwikkeling van interventiematerialen

Op basis van de resultaten uit fase 0 ontwikkelden we een preliminair interventiemodel. Tijdens fase 1 werden semigestructureerde interviews met leden van het palliatief thuiszorgteam en met oncologen georganiseerd om feedback te geven op het model. Voorts hielden we 4 workshops met stakeholders die verschillende groepen vertegenwoordigden (vb. patiënten, mantelzorgers, beleidsmakers). De bedoeling van deze participatorische aanpak was om te brainstormen hoe het interventiemodel geoptimaliseerd kon worden. Tot slot werd het model gefinetuned tijdens maandelijkse bijeenkomsten van een multidisciplinair onderzoeksteam bestaande uit psychologen, sociologen en een medisch oncoloog.

Fase 2: evalueren van de nieuwe interventie in een pre-post studie in termen van haalbaarheid, aanvaardbaarheid en preliminaire effectiviteit

De haalbaarheid en aanvaardbaarheid van de interventie werd vooreerst nagegaan in interviews met patiënten, mantelzorgers, huisartsen en oncologen die hadden deelgenomen aan de interventie en met het betrokken palliatief thuiszorgteam. Ook werd het aantal bezoeken door het palliatief thuiszorgteam bijgehouden, de inhoud van de conversaties en de tijd besteed aan verschillende onderwerpen. Voorts werd geregistreerd hoe vaak er contact was geweest tussen zorgverleners en wat de aanleiding hiervoor was geweest. De preliminaire effectiviteit tot slot werd gemeten met vragenlijsten die naar levenskwaliteit, gemoedstoestand en tevredenheid van zorg van patiënten en mantelzorgers peilden en die op baseline en na 12, 18 en 24 weken werden ingevuld.

BELANGRIJKSTE BEVINDINGEN

Verschillen tussen vroege en late inschakeling van palliatieve thuiszorg in de oncologische zorg (hoofdstuk 2)

In dit kwalitatief onderzoek werden focusgroepen met palliatieve thuiszorgteams (N = 6) uitgevoerd om inzicht te krijgen in de verschillen tussen vroeg en laat ingeschakeld worden van een palliatief thuiszorgteam in de oncologische zorg en de effecten dat vroeg ingeschakeld worden met zich meebrengt op de werking van het team en de vaardigheden van de zorgverleners. Uit de resultaten blijkt dat een shift van een medische aanpak naar een meer holistische aanpak het opvallendste verschil is. Naast een focus op problemen oplossen zoals vaak gebeurt bij late inschakeling, is er bij vroege inschakeling ook ruimte om te focussen op toekomstige doelen en wensen. Ook is er meer ruimte om niet enkel te focussen op pijn- en symptoomcontrole, maar ook op psychologische, sociale en existentiële thema's. Voorts zien we dat vroegere inschakeling resulteert in meer structuur bij het opvolgen van patiënten, waarbij patiënten worden bekrachtigd in het mee actief deel uitmaken van het beslissingsproces. Tot slot creëert vroegere inschakeling van palliatieve thuiszorg de nood aan transmurale samenwerking, hetgeen de teams aanzet om meer ondersteunende en coördinerende taken op zich te nemen zoals beschreven staat in hun taakomschrijving.

Barrières om palliatieve thuiszorg vroeger in het oncologisch traject te integreren (hoofdstuk 3)

Het kwalitatief onderzoek met palliatieve thuiszorgteams (N = 6) gaf voorts ook inzichten in de aanwezige barrières om palliatieve thuiszorg vroeger in het oncologisch traject te integreren. De resultaten bevestigen veel barrières die reeds in vorige studies rond barrières voor vroege palliatieve zorg zijn beschreven. Zo blijkt het gebrek aan financiële middelen bij een systematische vroege inschakeling een grote zorg te zijn. De bestaande maatschappelijke perceptie van palliatieve zorg als zijnde terminale zorg wordt tevens gezien als een grote barrière, resulterend in terughoudendheid bij artsen om patiënten door te verwijzen naar gespecialiseerde palliatieve zorg en bij een negatieve attitude van patiënten en mantelzorgers tegenover palliatieve zorg. Verder wordt een gebrek aan kennis bij oncologen over de inhoud en de rol die een palliatief thuiszorgteam kan spelen in een ziektetraject bevestigd door dit onderzoek. Maar ook zorgverleners werkzaam in de thuiscontext missen belangrijke informatie die nodig is om optimale palliatieve zorg te leveren vroeg in het traject, namelijk informatie over oncologische behandelingen en neveneffecten van deze behandelingen. Tot slot toont dit onderzoek dat de discontinuïteit van de zorg een extra uitdaging vormt voor het integreren van de thuiscontext in de ziekenhuiscontext. Een gebrek aan een duidelijke communicatiestructuur en een gedeeld communicatiekanaal, alsook een gebrek aan centrale coördinatie van het zorgtraject zorgen voor deze discontinuïteit van zorg.

De ontwikkeling van een complexe interventie (de EPHECT interventie) om de vroege integratie van palliatieve thuiszorg in de oncologische zorg te bevorderen: een Fase 0-1 studie (hoofdstuk 4)

Het integreren van de thuiscontext in de ziekenhuiscontext is een complex proces waarin verschillende settings, contexten en disciplines zijn betrokken. Een complexe interventie volgens de richtlijnen van het MRC Framework is dan ook aangewezen om de vroege integratie van palliatieve thuiszorg in de oncologische zorg te vorderen. In Fase 0 van dit Framework werden twee methoden gebruikt om de sleutelcomponenten voor de interventie te identificeren. Ten eerste werd een screening van de literatuur uitgevoerd naar bestaande en effectieve modellen van vroege integratie van palliatieve zorg in de oncologische zorg om te komen tot componenten die teruggevonden werden in de verschillende interventiemodellen. De gemeenschappelijke componenten van succesvolle interventies waren: 1) regelmatige consultaties door een zorgverlener van het palliatief zorgteam bij patiënten, 2) semigestructureerde gesprekken met een focus op zowel symptoomcontrole als psychosociale zorg en 3) educatie voor betrokken zorgverleners rond probleemoplossing en vertrouwd geraken met de interventiematerialen. Ten tweede werden focusgroepen met bestaande palliatieve thuiszorgteams (N = 6) georganiseerd om te reflecteren op de verschillen tussen vroeg ingeschakeld worden en laat ingeschakeld worden, op de bestaande barrières voor vroege palliatieve thuiszorg en op de sleutelcomponenten van de succesvolle interventies. Vervolgens werd in Fase 1 een interventie gemodelleerd door het selecteren van de belangrijkste componenten op basis van de resultaten uit de screening van de literatuur en de focusgroepen uit Fase 0. De uiteindelijk ontwikkelde interventie bestaat uit vijf componenten:

1. Trainingssessies voor betrokken zorgverleners
2. Huisarts fungeert als coördinator van het zorgtraject
3. Regelmatige en gestructureerde consultaties bij de patiënt thuis of op plaats naar voorkeur van de patiënt door een verpleegkundige van het palliatief thuiszorgteam
4. Een semigestructureerde gesprekshandleiding om de gesprekken te faciliteren
5. Gestructureerde interprofessionele en transmurale samenwerking

Is vroege integratie van palliatieve thuiszorg in de oncologische zorg haalbaar en aanvaardbaar? (hoofdstuk 5)

We hebben het interventiemodel van de EPHECT interventie getest in een Fase 2 pre-post studie waarin 30 patiënten met geavanceerde kanker uit de regio Brussel-Halle-Vilvoorde gedurende zes maanden zijn gevolgd door het regionaal palliatief thuiszorgteam. Belangrijkste doelstellingen van deze studie waren het testen van de haalbaarheid en aanvaardbaarheid van de studieprocedures (i.e. rekruteringsmechanismen, inclusiecriteria), de haalbaarheid en aanvaardbaarheid van de componenten van de EPHECT interventie, en het exploreren van de preliminaire effectiviteit van de interventie op de levenskwaliteit van patiënten en hun mantelzorgers. De resultaten van dit onderzoek tonen aan dat de vroege integratie van palliatieve thuiszorg in de oncologische zorg over het algemeen haalbaar en aanvaardbaar is voor patiënten, mantelzorgers en professionele zorgverleners.

Hoe vroege palliatieve thuiszorg introduceren bij gevorderde kankerpatiënten: lessen uit een fase 2 studie (hoofdstuk 6)

Na de interventie werden interviews gehouden met patiënten, mantelzorgers en professionele zorgverleners. We hebben onderzocht wat de percepties waren van patiënten en mantelzorgers over het betrokken worden in een vroege palliatieve thuiszorginterventie en of hun perceptie van palliatieve zorg veranderd is door de interventie. Voorts hebben we hun ideeën bevraagd over wanneer vroege palliatieve zorg idealiter moet worden opgestart. De meeste patiënten hadden negatieve gevoelens bij de eerste introductie van de interventie. Tijdens en na de interventie echter werden patiënten positiever ten opzichte van palliatieve zorg. Maar hun negatieve gevoelens tegenover de term bleven wel. Palliatieve zorg hernoemen tot supportieve zorg zou volgens de participanten een barrière wegnemen om over palliatieve zorg te beginnen praten. Uit deze studie bleek echter dat verschillende patiënten niet volledig op de hoogte waren van hun diagnose en prognose, wat een grote barrière bleek te zijn om over vroege palliatieve zorg te beginnen. Er is dus meer nodig dan enkel een naamsverandering. Duidelijke communicatie over diagnose en prognose en over de meerwaarde van palliatieve zorg is nodig en de positieve effecten van palliatieve zorg moeten gedeeld worden met het grote publiek. Volgens zorgverleners en patiënten mag palliatieve zorg reeds opgestart worden vanaf diagnose van gevorderde kanker. Niet voor intensieve begeleiding, wel voor kennismakingsgesprekken zodat patiënten en mantelzorgers weten waar ze terecht kunnen.

BESPREKING VAN DE BEVINDINGEN

Bestaande barrières voor vroege palliatieve thuiszorg

Palliatieve zorg wordt dus nog al te vaak gezien door patiënten, mantelzorgers en professionele zorgverleners als zijnde terminale zorg. Ook al werd de interventie positief geëvalueerd, dan nog bleven de negatieve gevoelens ten opzichte van de term palliatieve zorg. Een belangrijke barrière is het gebrek aan accurate informatie over diagnose en prognose bij patiënten. Tijdens de interventie werden patiënten positiever tegenover palliatieve zorg en dit omdat de bezoeken van de verpleegkundige hen deden inzien en aanvaarden dat ze een ongeneeslijke ziekte hadden. Dit pleit voor betere communicatie tussen oncologen en patiënten over prognose en het ongeneeslijke karakter van de ziekte. Voorts dienen de inhoud en meerwaarde van palliatieve zorg gedeeld te worden met het grote publiek, alvorens veranderingen in gedrag teweeg gebracht kunnen worden in het stigma rond palliatieve zorg.

Een tweede barrière is de discontinuïteit tussen zorgsettings. In de EPHECT interventie werd telefonisch contact gebruikt om communicatie tussen settings te faciliteren. Maar uit de resultaten blijkt dat we faalden in het verbeteren van interdisciplinaire samenwerking. Op basis van deze bevindingen moet het interventiemodel worden aangepast om optimale geïntegreerde palliatieve zorg na te streven. De ontwikkeling van multidisciplinaire meetings waarop verschillende disciplines en zorgsettings samenkomen is nodig om vroege doorverwijzing naar palliatieve thuiszorg te faciliteren en continuïteit van zorg te garanderen.

Een zorg die palliatieve thuiszorgteams in de focusgroepstudie deelden was het gebrek aan financiële middelen moest palliatieve thuiszorg systematisch worden aangeboden aan alle patiënten met gevorderde kanker. Uit de analyse van onze interventie blijkt echter dat patiënten gemiddeld vier keer werden bezocht door een verpleegkundige van het palliatief thuiszorgteam, veel minder dan de vooropgestelde maandelijkse bezoeken. Volgens patiënten en professionele zorgverleners waren kennismakende gesprekken systematisch nodig in het begin van het traject om een band op te bouwen en rapport te installeren. Zolang nadien de situatie echter stabiel bleef, waren deze systematische bezoeken echter niet nodig. Wij adviseren daarom om in plaats van gespecialiseerde palliatieve zorg standaard aan iedereen aan te bieden, een model waarin gespecialiseerde palliatieve zorgteams zichzelf gaan voorstellen bij de patiënt zodat zij weten waar ze terecht kunnen indien nodig. Follow-up wordt echter gepland op basis van de noden van patiënten en mantelzorgers.

Inhoud en structuur van vroege palliatieve zorg

Analyses van de gesprekshandleidingen tonen aan dat de eerste bezoeken voornamelijk gefocust waren op ziektebegrip, installeren van rapport en het opbouwen van een vertrouwensrelatie tussen de patiënt, mantelzorger en de verpleegkundige van het palliatief thuiszorgteam. Installeren van rapport in het begin is cruciaal om later meer sensitieve topics aan te snijden. Vroeger betrokken worden geeft palliatieve thuiszorgteams de kans om holistische zorg te leveren en meer tijd te spenderen aan andere topics dan enkel symptoomcontrole. Dit laatste is vaak het geval wanneer palliatieve thuiszorgteams pas laat in het traject worden betrokken. Gespecialiseerde palliatieve zorgteams moeten vroeger betrokken worden om zo meer tijd en ruimte te geven om een gestructureerde en graduele opbouw toe te laten in de bezoeken om later sensitieve onderwerpen te bespreken. Door het maken van kleine aanpassingen aan de huidige zorg – vroeger inschakelen en thuisbezoeken structureren en gradueel opbouwen – zijn huidige palliatieve thuiszorgteams in staat om vroege palliatieve zorg te geven aan gevorderde kankerpatiënten.

Doorverwijzing naar vroege palliatieve zorg: gebaseerd op prognose of op noden?

In de EPHECT interventie moesten oncologen een inschatting maken van een levensverwachting van 6 tot 24 maanden bij het screenen van patiënten geschikt voor de interventie. Ze gaven achteraf echter aan dat het moeilijk is een verwachting van langer dan 6 maand in te schatten. Zoals bevestigd door deze studie, hebben oncologen het vaak moeilijk met het correct inschatten van levensverwachting. Voorts zullen patiënten door steeds nieuwe antikankerbehandelingen langer leven met kanker en kanker zal meer en meer een ziekte worden met een chronisch verloop. Ook toont onderzoek aan dat patiënten al vroeg in het ziektetraject palliatieve zorgnoden kunnen hebben. Al dit pleit voor een doorverwijzing naar gespecialiseerde palliatieve zorg op basis van noden. Professionele zorgverleners hebben het echter vaak moeilijk om deze noden te identificeren of het gesprek te starten. Daarom zijn tools nodig om hen hierin te ondersteunen. Het gebruik van PROM’s zou hen hierbij kunnen helpen.

Heeft vroege integratie van palliatieve thuiszorg in de oncologische zorg positieve effecten op de levenskwaliteit van patiënten en naasten?

De subjectieve percepties van patiënten en mantelzorgers tonen dat de EPHECT interventie positieve effecten heeft op verschillende domeinen van levenskwaliteit wat leidt tot de assumptie dat de interventie kwaliteit van leven van patiënten en mantelzorgers positief beïnvloedt. Opvallend is echter dat de angstscores van mantelzorgers hoog waren en bleven tijdens de interventie. Sommigen hadden ook het gevoel dat de verpleegkundige er vooral was voor de patiënt en niet of minder voor hen. Toekomstige interventies moeten meer gericht zijn op de patiënt-mantelzorger dyade in plaats van de levenskwaliteit van mantelzorgers als bijkomstig doel te zien.

Wat leren we uit dit doctoraat voor toekomstig onderzoek naar vroege integratie van gespecialiseerde palliatieve (thuis)zorg?

Het huidige interventiemodel is niet haalbaar en duurzaam genoeg om getest te worden in een grootschalige gerandomiseerde fase 3 studie. Het model ‘gespecialiseerde zorg voor iedereen’ is niet haalbaar voor gespecialiseerde palliatieve teams met hun huidige financiering en middelen.

Palliatieve zorg moet gezien worden als deel van de standardzorg voor gevorderde kankerpatiënten, waarbij patiënten gebruik kunnen maken van het team op elk moment in het ziektetraject. Palliatieve zorgteams moeten zichzelf voorstellen aan patiënten en mantelzorgers door een paar bezoeken in te plannen in het begin van het traject om zo een vertrouwensrelatie op te bouwen. Op deze manier kunnen barrières verlaagd worden om het team te contacteren wanneer het nodig is.

Voorts dient de generalistische palliatieve zorg versterkt en uitgebreid te worden. Door gebruik te maken van PROMs, dient systematisch assessment van zorgnoden gedaan te worden door de oncoloog of de huisarts tijdens hun consultaties. Op deze manier kan gescreend worden op palliatieve zorgnoden en kunnen deze behandeld worden. Wanneer ze te complex zijn, kan de patiënt op basis van deze screening doorverwezen worden naar gespecialiseerde palliatieve zorg. Eens gestabiliseerd, kan de follow-up worden opgenomen door de oncoloog of de huisarts met gespecialiseerd advies en ondersteuning van het palliatief team.

Dit model vereist een intense samenwerking tussen de primaire, secundaire en tertiaire palliatieve zorgverlening. De ontwikkeling van een gedeeld elektronisch dossier is essentieel om continuïteit van zorg te garanderen. Voorts moet een manier gevonden worden om disciplines van verschillende zorgsettings bij elkaar te brengen om zo de zorgnoden van patiënten en de daarop aangepaste verdere zorg te bespreken.

Suggesties voor verder onderzoek

Verschillende vragen blijven onbeantwoord na dit doctoraat en zijn handvaten voor toekomstig onderzoek:

- Wat is de optimale structuur en frequentie van de thuisbezoeken door het palliatief thuiszorgteam?
- Wat is het meest haalbare level van integratie en wat is hiervoor nodig om dit te bereiken?
- Wat is het beste model om gespecialiseerde palliatieve zorg te introduceren bij alle patiënten vanaf diagnose van gevorderde kanker?

Voorts dient de EPHECT interventie aangepast te worden op basis van de bevindingen uit dit doctoraat om dan getest te worden in een grootschalige gerandomiseerde studie.

In toekomstige interventies moet gefocust worden op de mantelzorger als zijnde een zorgverlener voor zijn of haar partner en als zijnde een zorgvrager.

Implicaties voor het beleid

Verhogen van het bewustzijn rond de meerwaarde en de inhoud van vroege palliatieve zorg

Verhogen van vaardigheden in palliatieve zorg voor professionele zorgverleners

Faciliteren van interprofessionele samenwerking

Uitbreiden van de financiële middelen voor gespecialiseerde palliatieve zorgteams

Implicaties voor de praktijk

Leveren van holistische palliatieve zorg aan patiënten vanaf diagnose van gevorderde kanker

Doorverwijzing naar gespecialiseerde palliatieve zorg op basis van noden en niet op basis van prognose

Systematische consultaties van een gespecialiseerd palliatief zorgteam vanaf diagnose om vertrouwensband op te bouwen met patiënt en mantelzorger

Meer aandacht aan de duale positie van de mantelzorger als zijnde zorgvrager én zorgverlener

Curriculum Vitae and list of publications of Naomi Dhollander

CURRICULUM VITAE

Naomi Dhollander, born September 24, 1991 (Sint-Niklaas, Belgium) obtained her Master's degree in clinical psychology in 2014 (Ugent). During her Master, she did an internship as onco-psychologist in Ghent University Hospital and after that, she worked as an onco-psychologist at AZ Damiaan in Oostende. Since 2015, she is associated as a researcher at the End-Of-Life Care Research Group of the Ghent University & the Vrije Universiteit Brussel.

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