

## Phase 0-1 early palliative home care cancer treatment intervention study

Dhollander, Naomi; Smets, Tinne; De Vleminck, Aline; Van Belle, Simon; Deliëns, Luc; Pardon, Koen

*Published in:*  
BMJ Supportive and Palliative Care

*DOI:*  
[10.1136/bmjspcare-2018-001716](https://doi.org/10.1136/bmjspcare-2018-001716)

*Publication date:*  
2022

*Document Version:*  
Accepted author manuscript

[Link to publication](#)

### *Citation for published version (APA):*

Dhollander, N., Smets, T., De Vleminck, A., Van Belle, S., Deliëns, L., & Pardon, K. (2022). Phase 0-1 early palliative home care cancer treatment intervention study. *BMJ Supportive and Palliative Care*, 12(e1), e103-e111. <https://doi.org/10.1136/bmjspcare-2018-001716>

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## **Development of the Early Palliative Home care Embedded in Cancer Treatment (EPHECT) intervention: phase 0-1.**

Naomi Dhollander<sup>1</sup>, Tinne Smets<sup>1</sup>, Aline De Vleminck<sup>1</sup>, Simon Van Belle<sup>1,2,3</sup>, Luc Deliens<sup>1,4\*</sup>, Koen Pardon<sup>1\*</sup>

\*Both contributed equally to this work.

<sup>1</sup> End-of-life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University, Brussels, Belgium

<sup>2</sup> Department of Medical Oncology, Ghent University Hospital, Ghent, Belgium

<sup>3</sup> Palliative Care Team, Ghent University Hospital, Ghent, Belgium

<sup>4</sup> Department of Public Health and Primary Care, Ghent University Hospital, Ghent, Belgium

### **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 transmurals 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.



## **Manuscript**

### **Background**

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.<sup>1,2</sup> Palliative care can mitigate these problems, but is usually only provided late in the course of the disease when death is imminent.<sup>3-5</sup> 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.<sup>6-10</sup>

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.<sup>11</sup> A recent systematic literature review shows that the majority of cancer patients prefer to be cared for and die in their own homes.<sup>12</sup> 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.<sup>13</sup> 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<sup>14</sup>.

Our previous study based on focus groups done with PHC teams in Belgium shows that in a model of early integrated care, i.e. the concurrent provision of oncology and palliative care, the palliative care team has to spend less time on symptom management which is provided by the oncology team and the GP. 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.<sup>15-19</sup> 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<sup>20</sup>. Inter-professional and transmurall 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<sup>21</sup>).

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.



## **Methods**

### **Study design**

The intervention development followed the guidance of the Medical Research Council (MRC) framework for development and evaluation of complex interventions.<sup>17</sup> 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.<sup>22,23</sup> 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<sup>24</sup>. 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 cluster-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<sup>25</sup>. We only included trials that were tested on their effectiveness for different outcomes and that showed 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.<sup>26</sup> The model was further refined at monthly meetings with the multidisciplinary research team consisting of psychologists, sociologists and a medical oncologist.

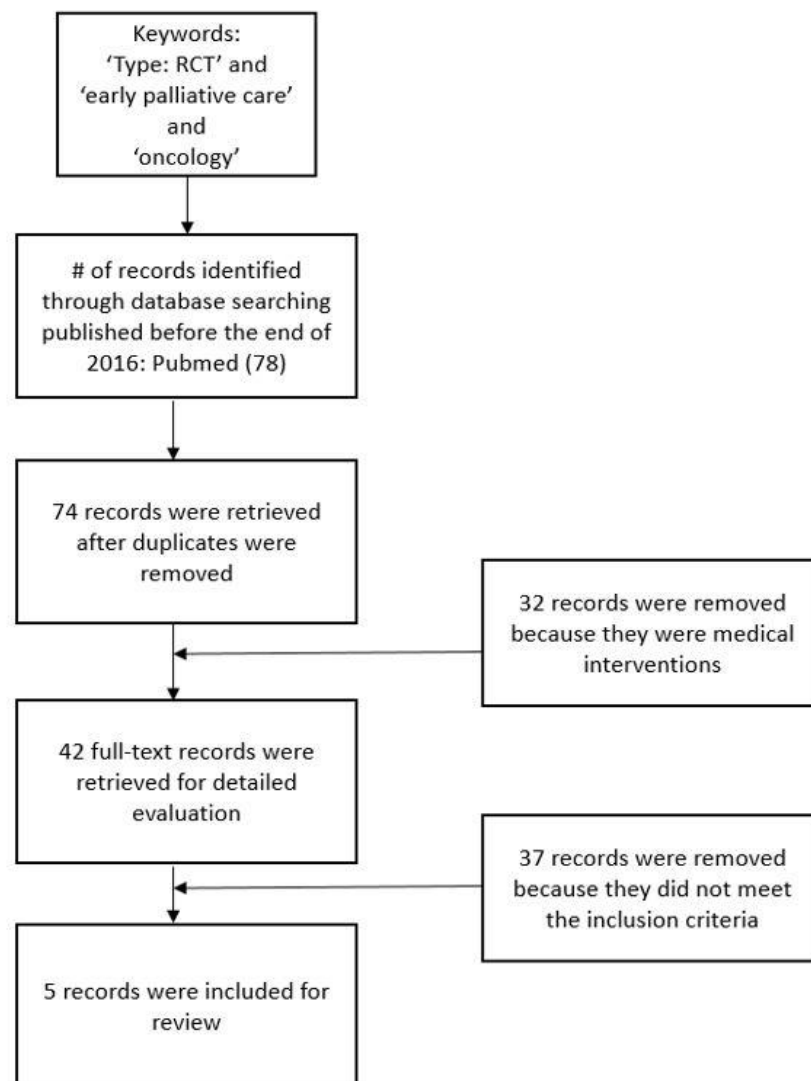
## **Results**

### **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<sup>6-8</sup>, one in Canada<sup>10</sup>, and one in Italy<sup>9</sup> (Table 2). Two of the interventions for early integration of palliative care were developed for the hospital setting<sup>8,10</sup>, and three for outpatient clinics<sup>6,9,27</sup>. 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<sup>8</sup> or pancreatic cancer<sup>9</sup>, others included different cancer diagnoses<sup>6,7,10</sup>. Studies also differed on the expected survival time, with variations between two months<sup>9</sup> and two years<sup>10,27</sup>.





**Figure 1: full electronic search strategy**

Based on the screening of these seven 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.<sup>6-10</sup> 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<sup>6,27</sup>.

*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<sup>8,9</sup>; 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<sup>6,27</sup>. In some interventions the Distress Thermometer<sup>6,27</sup> or the Edmonton Symptom Assessment System<sup>8-10</sup> 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<sup>6,7</sup>. These involved a two-day training course on problem-solving and becoming familiar with the study materials<sup>6,7</sup>.

#### *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.<sup>28</sup>

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*

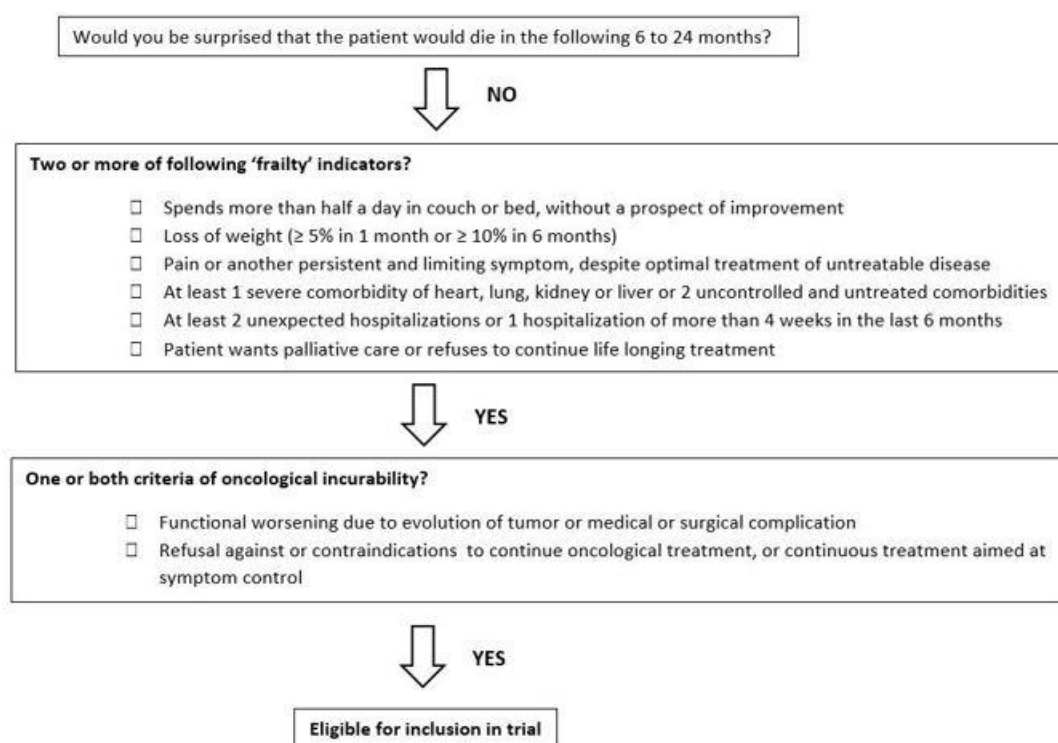
The participants of the focus groups expressed the need for better knowledge of oncological diseases and drug therapies. They thought that health professionals working in the home context lacked the oncological knowledge needed to provide optimal palliative care concurrent with active oncology care, 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)<sup>29</sup> to determine which patients are eligible for early PHC (Figure 2).



**Figure 2: prognosis- and needs-based criteria 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<sup>21</sup>. 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<sup>6,8,10,27,30</sup>, the guidelines of the National Consensus Project for Quality Palliative Care<sup>31</sup> and on the process evaluation of Temel's intervention which largely addressed symptom management, patient and family coping and illness understanding and education.<sup>32</sup> 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.<sup>33</sup>



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<sup>22</sup>. 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.<sup>34–36</sup> It allows researchers to identify the key components of interventions and to adopt the appropriate methods for evaluating them.<sup>22</sup>

A model for testing the effects of early integration of specialised palliative home care into oncology care is lacking<sup>14</sup>, 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.<sup>37</sup> 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<sup>4</sup> 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.<sup>38</sup>

Our intervention model is comparable with previous interventions in terms of some key components<sup>6–10</sup>. 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.<sup>39</sup>

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<sup>25</sup> implies that provision should be more needs-based than prognosis-based and according to a Delphi study<sup>40</sup> 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<sup>41</sup> 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.<sup>28</sup> 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.<sup>9,30</sup> However, only one recent intervention added structured collaboration as part of the intervention protocol by involving the palliative team in multidisciplinary meetings<sup>42</sup>. 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.<sup>43</sup> 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.<sup>42,44</sup> However, these do not include any components that were not included in our intervention model.<sup>42,44</sup>

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.



## Declarations

### *Authorship*

Naomi Dhollander<sup>1</sup>, Tinne Smets<sup>1</sup>, Aline De Vleminck<sup>1</sup>, Simon Van Belle<sup>1,2,3</sup>, Luc Deliens<sup>1,4\*</sup>, Koen Pardon<sup>1\*</sup>

\*Both contributed equally to this work.

<sup>1</sup> End-of-life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University, Brussels, Belgium

<sup>2</sup> Department of Medical Oncology, Ghent University Hospital, Ghent, Belgium

<sup>3</sup> Palliative Care Team, Ghent University Hospital, Ghent, Belgium

<sup>4</sup> Department of Public Health and Primary Care, Ghent University Hospital, Ghent, Belgium

### *Funding*

This work was supported by the Agency for Innovation by Science and Technology (IWT) as part of the INTEGRATE-project. [SBO-IWT 140009]

### *Declaration of conflict of interest*

The Authors declare that there is no conflict of interest.

### *Research ethics and patient consent*

The proposal for this study was submitted for approval to the commission of medical ethics of the university hospital of Ghent.

### *Data management and sharing*

The data of this study is kept by the first author and is available upon request.

### *Acknowledgements*

**Anne-Lore Scherrens and Charlotte Scheerens** were the junior researchers observing some of the focus groups.

**Jane Ruthven** provided language editing of the manuscript.

All **professional caregivers from the six palliative home care teams** who agreed to participate in one of the six focus groups.

### *Corresponding author contact details*



Naomi Dhollander, MSc.  
End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University  
[naomi.dhollander@ugent.be](mailto:naomi.dhollander@ugent.be)  
+32 (0)9 332 15 05  
De Pintelaan 185  
6K3, room 009  
9000, Gent – Belgium

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Phase	Methodology
<i>(A) Phase 0 – theory</i>	
(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
<i>(B) Phase 1 – modelling of EPHECT intervention</i>	
(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 <sup>6</sup>	Advanced cancer patients with prognosis of approximately 1 year – oncology clinics and outreach clinics (USA)	<p>Educate, Nurture, Advise, Before Life Ends (ENABLE) II</p> <ul style="list-style-type: none"> <li>- Nurse-led intervention</li> <li>- Telephone-based study</li> <li>- Manual given to patient “Charting your course” with 4 topics: problem solving, communication and social support, symptom management and Advance Care Planning</li> <li>- Weekly for four weeks, then monthly follow up</li> <li>- Each session: distress thermometer</li> <li>- Shared Medical Appointments (SMA) by PC physician and nurse practitioner with patient and family carer</li> </ul> <p>Education</p> <ul style="list-style-type: none"> <li>- Nurse educators trained in problem solving / meetings with study staff / meetings with trainer and supervisor</li> <li>- SMA: trained by expert</li> </ul>	<p><u>Patient</u></p> <p><b>Quality of life</b></p> <p>Symptom intensity</p> <p><b>Mood</b></p> <p><u>Survival</u></p> <p><u>Informal carer</u></p> <p>N.A.</p> <p><u>Resource use near end of life</u></p>
Bakitas et al <sup>7</sup>	Advanced cancer patients with prognosis of approximately 6 months to 2 years – fast track design (3 months later)	<p>ENABLE III</p> <ul style="list-style-type: none"> <li>- Initial in-person, outpatient PC consultation with PC physician</li> <li>- Six structured weekly telephone sessions by nurse</li> <li>- Manual patient “Charting Your Course” – extra: life-review approach</li> <li>- Monthly follow up calls</li> </ul> <p>Education</p> <ul style="list-style-type: none"> <li>- Nurse coach training: self-study, review of treatment manuals and scripts, role playing with feedback</li> </ul>	<p><u>Patient</u></p> <p>Quality of life</p> <p>Symptom intensity</p> <p>Mood</p> <p><u>Survival</u></p> <p><u>Informal carer</u></p> <p>Quality of life</p> <p><b>Mood</b></p> <p><b>Burden</b></p> <p><u>Resource use near end of life</u></p>
Maltoni <sup>9</sup>	Newly diagnosed metastatic pancreatic cancer with a life expectancy of more than 2 months – Italy	<p>Systematic early palliative care</p> <ul style="list-style-type: none"> <li>- Specialist and nurse led intervention</li> <li>- First: appointment with PC specialist with predefined checklist SAME as Temel (2010)</li> </ul> <p>Then: follow up every 2 to 4 weeks until death</p>	<p><u>Patient</u></p> <p><b>Quality of life</b></p> <p>Symptom intensity</p> <p>Mood</p>



		<ul style="list-style-type: none"> <li>- All appointments based on General PC guidelines</li> <li>- Recommendations made by PC expert on decision making had to be shared by oncologist</li> </ul>	<u>Survival</u> <u>Informal carer</u> N.A. <u><b>Resource use near end of life</b></u>
Temel <sup>8</sup>	Patients with metastatic non-small cell lung cancer	Early palliative care <ul style="list-style-type: none"> <li>- Meeting with member of PC team (nurse &amp; physician)</li> <li>- At least monthly visits following the guidelines of the National Consensus Project for Quality PC</li> <li>- Special attention to physical and psychosocial symptoms, goals of care, assisting with decision making, coordination of care</li> </ul>	<u>Patient</u> <b>Quality of life</b> Symptom intensity <b>Mood</b>  <u>Survival</u>  <u>Informal carer</u> N.A. <u><b>Resource use near end of life</b></u>
Zimmermann <sup>10</sup>	Patients with advanced cancer with a prognosis of approximately 6 months to 2 years	Early palliative care <ul style="list-style-type: none"> <li>- Interdisciplinary approach (PC nurse and physician)</li> <li>- Outpatient <ul style="list-style-type: none"> <li>o Routine visits monthly with routine structured symptom assessment</li> <li>o Attention to ACP</li> </ul> </li> <li>- Telephone-based follow up</li> </ul>	<u>Patient</u> <b>Quality of life</b> <b>Symptom intensity</b> <b>Satisfaction with care</b>  <u>Survival</u> N.A.  <u>Informal carer</u> Quality of life <b>Satisfaction with care</b>  <u><b>Resource use near end of life</b></u>

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
<p>Regular home visits by the PHC team</p> <ul style="list-style-type: none"> <li>- Once a week to at least monthly</li> <li>- In-person contact combined with telephone contact</li> </ul>	<ul style="list-style-type: none"> <li>- In-person contact was preferred</li> <li>- Monthly visits might be not enough for some patients or too much for others</li> </ul>	<ul style="list-style-type: none"> <li>- In-person consultations with patient and family caregiver</li> <li>- Recommendation of minimum one home visit per month, but to be discussed with patient in first consultation</li> <li>- Consultations can be supplemented with in-between telephone contacts if needed</li> </ul>
GP as coordinator of care	<ul style="list-style-type: none"> <li>- GP central coordinator of care, has to be the coordinator of the communication between home and hospital setting</li> </ul>	<ul style="list-style-type: none"> <li>- GP will be contacted by data nurse to give permission for introducing PHC to his/her patient</li> <li>- GP will then contact the PHC to plan the first visit</li> <li>- GP is the central coordinator of care and communicates with PHC team and oncologist</li> </ul>
<p>Semi-structured contacts focusing on the provision not only of symptom management but also of psychological and social care</p> <ul style="list-style-type: none"> <li>- Routine symptom screening</li> <li>- Communication guideline based on existing guidelines for quality palliative care or behavioural cognitive models</li> </ul>	<ul style="list-style-type: none"> <li>- Early involvement gives more time to pay attention to psychosocial and existential problems besides pain and symptom management</li> <li>- Already holistic approach, but home visits are not structured at this moment</li> </ul>	<ul style="list-style-type: none"> <li>- Semi-structured guide to be used in patient consultations in which following topics are embedded: <ul style="list-style-type: none"> <li>o Understanding and perception of illness</li> <li>o Routine symptom management (ESAS at each visit)</li> </ul> </li> </ul>



		<ul style="list-style-type: none"> <li>○ Organisation of care</li> <li>○ Coping mechanisms</li> <li>○ Quality of life of patient and family carer</li> <li>○ Preferences for future care</li> </ul>
<p>Education for involved professionals</p> <ul style="list-style-type: none"> <li>- Study materials</li> <li>- Problem-solving and communication strategies</li> </ul>	<ul style="list-style-type: none"> <li>- Agreement on familiarity with study materials</li> <li>- Palliative care specialists need more information about oncological therapies and side effects to provide optimal concurrent palliative care</li> <li>- Oncologists need more information about content of palliative care and the role of PHC when involved early</li> </ul>	<ul style="list-style-type: none"> <li>- 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</li> <li>- Training for PHC team in working with intervention materials</li> <li>- Involved oncologists will be informed about working procedures and role of PHC team</li> </ul>
<p>Inter-professional and transmutal collaboration</p> <ul style="list-style-type: none"> <li>- Mentioned in some interventions as important but without any guidelines or structure</li> </ul>	<ul style="list-style-type: none"> <li>- Preferences for personal contact between professional caregivers, although telephone contact will be the easiest way</li> </ul>	<ul style="list-style-type: none"> <li>- Collaboration and communication via telephone contacts</li> <li>- Patients will be discussed by the PHC team during weekly meetings</li> <li>- GP will be contacted after each home visit and if needed after weekly meeting</li> <li>- If needed, GP will contact oncologist to discuss further actions</li> </ul>

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



## Appendix: supplementary figure

**Figure 1: Semistructured 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