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

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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 group 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 transmutal 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 transmutal 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.

Keywords

Cancer, early palliative care, palliative home care, integrated care, medical oncology, qualitative research

What is already known about the topic?

- Early palliative care integrated into oncology care leads to positive effects on the quality of life of the person who is dying and on their survival time.
- No randomised controlled trials on the integration of specialised palliative home care in oncology care have yet been identified.
- Information on the key components necessary for the integration of palliative care in the home setting is lacking, as well as information on the ways in which early involvement has an effect on the skills and working procedures of palliative home care teams.

What this paper adds?

- Being involved earlier leads to different tasks and working procedures for a palliative home care team and to the need for transmutal collaboration, something not found with early integration of palliative care in the hospital setting.
- To develop an integration model applicable to the Belgian home care system, existing models of early integrated care in the hospital setting can be used, but at some points extensions and/or adaptations are required.

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Implications for practice, theory or policy

- 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.
- Early involvement leads to the need for transmurial collaboration. Latest developments in communication methods should be evaluated to find a shared communication platform applicable to all disciplines.
- Future research should focus on the development of an intervention model for the early integration of palliative home care in oncology care.

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 provided not only 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 15–20 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 the quality of life of people with advanced cancer.

Method

Design

In order to explore the individual experiences of professional caregivers, we chose the most appropriate research design, that is, 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 perspectives¹⁵ while stimulating reflection and discussion between professionals. This article follows the criteria for reporting qualitative research from the Consolidated Criteria for Reporting Qualitative Research (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.

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

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

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 1 h and were moderated by N.D. and observed by junior or senior researchers making field notes.

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 (L.D., A.D.V.), psychologists (N.D., K.P.) and a medical oncologist (S.V.B.). 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 article 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 (N.D. and A.D.V.). Following an inductive approach, the constant comparative method was used to compare fragments within and between focus groups.^{17,18} First, 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, N.D. and A.D.V. coded the transcripts using the final version of the conceptual coding 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)

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

Characteristics	Number of participants						Total
	FG1	FG2	FG3	FG4	FG5	FG6	
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 (years)							
≤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

FG: focus group.

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 and 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. (FG1, 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, for example, allowing time for the process of acceptance.

Advance care planning. Most participants feel that earlier involvement makes conversations about advance care planning (ACP) more likely. Although patients might live for years, that does not 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 given not only 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 and conclusion

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 World Health Organization (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 et al.,¹ developed in the hospital setting. In this intervention, the palliative care team visited the patients in the intervention arm at least monthly. Yoong et al.²¹ 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.

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.

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.²² Furthermore, according to our participants and previous research, a systematic structure can be seen in topics discussed during the home visits.^{21,23} 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.²⁴

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 transmutal 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 transmutal 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.^{15,25} 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 GPs) 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.

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Data management and sharing

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

Declaration of conflicting interests

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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.

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