



Patients' experiences of transfers between care settings in palliative care: an interview study

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Background: Palliative patients often suffer from serious illness and commonly move between care settings. As such, transfers of patients can take place between acute hospital based care and community based care in both directions. The involvement of multiple caregivers providing care across settings causes fragmentation of care. To address this challenge and to optimize coordination and continuity of care, we explored experiences of palliative patients regarding their transfers between care settings and the perceived role of the treating family physician.

Methods: Qualitative interview study of 20 palliative patients. Participating settings were the hospital and hospitals' palliative care unit, the nursing home, the home care setting and the palliative day care centre. A constant comparative method was used to analyze data.

Results: Although the home was considered the preferred residence, perceptions of unsafety arose in cases of increased symptom burden and when the organization of home care was insufficiently geared to the patients' needs. Both the nursing home and the palliative care unit offered safety and good care when home residence became unfeasible. Upon hospital admission, experiences did not always meet expectations, varying significantly depending on the hospital, type of ward and reason for hospitalization. Perceived issues regarding hospital discharge were premature release, lack of seamless care and home care insufficiently tailored to the patients' needs. The family physician's role assignment ranged from pivotal to minimal. Patients especially expected their family physician to guarantee continuity of care.

Conclusions: Home is considered the preferred place of long-term care, as long as it is perceived a safe environment. A person-centered approach, focusing on the patient's complex needs, is not consistently implemented in palliative care settings. Barriers in inter-professional collaboration need to be tackled to provide high quality care across settings.

Keywords: Palliative care; qualitative research; patient experiences; patient transfers; interview study

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Introduction

The number of patients with complex palliative care needs is increasing in developed countries due to population ageing, a higher number of people living with chronic conditions and comorbidities and the improvement of disease treatment (1). Patients with palliative care needs also often suffer from serious illness and due to the fluctuating burden of illness, they commonly move between care settings (e.g., from home or the nursing home to the hospital, to receive life-prolonging treatment, or to treat exacerbating symptoms) (2-4). Such transfers can take place between hospital-based care and community-based care in both directions. Some of these transfers can be considered necessary or justified (e.g., due to certain medical conditions that can be managed at the hospital only, or in situations of inadequate caring capacity) (5), while others—especially between the home and the hospital—can be inappropriate or potentially avoidable (e.g., due to the ‘rescue culture’ of modern medicine or the inadequate availability of community services) (6,7). As a consequence of these transfers across settings, multiple caregivers with various professional backgrounds are involved, resulting in a fragmentation of care. This fragmentation poses a challenge on the coordination and the continuity of care (8-11). Lack of continuity of care may result in undesired experiences with palliative care provision (e.g., feeling unsafe during a sudden progression of disease burden or perceived suboptimal support for problems and needs) (9,12). By contrast, strong continuity of care for patients with palliative care needs is associated with lower rates of emergency department visits, decreased hospital deaths and supportive needs being met (9).

A majority of the palliative patients prefers to remain and die at home, in familiar surroundings and being cared for by the family physician with whom they often have long-standing relationships (13). Family physicians have a coordinating role in patient care, providing high-quality responsive care across the lifecycle as well as assuring continuity and collaboration with other health care providers (14). As such, they play a key role in palliative care (15,16). Many family physicians consider palliative care to be part of their job responsibilities and get satisfaction out of the task (17,18).

Regarding the organization of palliative care, services have, in recent years, increased in number and type under the impulse of the World Health Organization (WHO) (19,20). In Flanders, Belgium, palliative care services exist since 1995.

An overview of palliative care organization and services in Belgium is described below. Similar services and organizations of palliative care can be found within Europe (21).

This study is part of a research project that concentrates on palliative care provided within one of the fifteen palliative care networks in Flanders. To optimize continuity of care and the care coordination for palliative patients during transfers within a palliative care network, we explored experiences of 53 healthcare professionals (22), 20 patients and 21 informal caregivers. This paper reports the experiences of the patients regarding their transfers between care settings and the role of the treating family physician.

From the perspective of the palliative patient, the research questions addressed within this context were:

- ❖ What factors are perceived to influence the decision to move to another care setting?
- ❖ How do patients perceive the way care settings respond to their needs?
- ❖ What are the expectations of patients towards the treating family physician in guiding the transfer?

Considering the importance of continuity of care and care coordination across settings during palliative patient's transfers, various studies have already been carried out. Care provided and care setting transitions in the last three months of life of cancer patients have been studied by Ko *et al.* (3). The results were based on reports of family physicians. A systematic review of Saunders *et al.* (11) reported on palliative care transitions from acute care to community-based care, however did not include other palliative care services. Likewise, the study of Morey *et al.* (10), describing patient and caregiver perceptions of continuity of care and the study of Flierman *et al.* (23) reporting on health care providers' views regarding transfers from hospital to palliative care at home. Patients' perceptions of palliative care quality in hospice inpatient care, hospice day care, palliative units in nursing homes and home care have been investigated in the cross-sectional study of Sandsdalen *et al.* (24). Sandsdalen *et al.* provide important insights into the patients' perceptions of care quality within and across settings, however their study was based on quantitative research data (24). Despite the above-mentioned literature, studies that not only examine transfers between multiple settings in palliative care but also use a qualitative research approach and focus on the patient's perspective, are scarce. We aimed to fill this gap, in order to fully understand the perspectives of patients regarding their transfers between care settings in palliative care.

Overview of the definition of palliative care and the recent trends in palliative care organization within the WHO region of Europe

According to the definition of the WHO (25), palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical psychosocial and spiritual. Palliative care:

- ❖ Provides relief from pain and other distressing symptoms;
- ❖ Affirms life and regards dying as a normal process;
- ❖ Intends neither to hasten or postpone death;
- ❖ Integrates the psychological and spiritual aspects of patient care;
- ❖ Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- ❖ Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- ❖ Will enhance quality of life, and may also positively influence the course of illness;
- ❖ Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (25).

Although the need for palliative care is increasing worldwide, it is only beginning to be available in developing countries, where family caregivers play a central role in managing care at home due to the inadequate access to care (26,27).

In Europe, it has been promoted that health care systems should differentiate palliative care into generalist palliative care and specialized palliative care. General palliative care should be provided by all health and social care professionals, while specialist palliative care should be limited to more complex challenges in symptom control and promotion of quality of life and should be provided by healthcare professionals with specialist or accredited training in palliative care (28). According to the European Association for Palliative Care (EAPC), the estimated number of specialized services required to cover the basic needs of palliative care patients are: at least one hospital palliative support team and one inpatient palliative care

service per 200,000 inhabitants, and one home care team per 100,000 inhabitants (29). A recent analysis of trends in the organization of specialized palliative care services in the WHO European region showed an increasing ratio of specialized service provision in the last 14 years (29). However, inequalities were reported, with high-income countries achieving a major increase (in all types of services) compared to a little increase (only for inpatient services) for low-to-middle-income countries. Central-Eastern European countries showed significant improvement in home care teams and inpatient services, while Western countries showed significant improvement in hospital support and home care teams. Home care was the most prominent service in Western Europe (29).

Palliative care in Flanders, Belgium (30,31)

Palliative care in Flanders is organized in 15 regional networks, each coordinating the palliative care of the region covered. Palliative home care teams are autonomous entities, functioning within these regional networks. They provide support and consultation about all aspects of palliative care to patients, their family members and primary healthcare providers (e.g., the family physician, community nurses, nursing home nurses). The majority of the home visits by the palliative home care team is carried out by specialized palliative home care team nurses, whereas palliative home care team physicians and psychologists support and advise palliative home care team nurses during weekly team meetings. Palliative day care centres are complementary to primary home care; a multidisciplinary team gives patient support and can offer support to a patient's family. Only patients with an incurable, progressive and terminal disease with a maximum remaining life expectancy of one year that are not residents of a nursing home may come to these centres. Belgium has 6 recognized palliative day care centres, of which 5 are situated in Flanders. Within nursing homes, the coordinating physician, together with a head nurse and a palliative reference person (mostly a nurse) are responsible for guaranteeing a culture of palliative care and for offering advice to the nursing home personnel. Within the hospital setting, two palliative care services are present. The first is a palliative care unit, consisting of 6–12 beds. The second is a palliative support team, a multidisciplinary mobile team that provides second-line consultation to hospital staff with regard to palliative care management for patients not staying at the palliative care unit.

Methods

Design

A qualitative design was chosen, using semi-structured interviews. This article follows the COREQ reporting checklist (available at <https://apm.amegroups.com/article/view/10.21037/apm-22-146/rc>) (32).

Settings and participants

All types of care settings within the palliative care network of the covered region were included in the research project: the patients' home, the nursing homes and the hospital setting.

The region, with a population of 264,000 has one regional palliative home care team (PHCT), 34 nursing homes and 4 hospitals. All four hospitals have a palliative support team (PST) and the largest hospital also has a palliative care unit (PCU) with 9 beds. The regional PHCT, two nursing homes and two hospitals were selected to participate in this research project. The largest hospital was selected because of its PCU; the selection of the second hospital was based on the largest number of patients receiving PST support. The nursing homes selection was based on its size (largest). In addition to the home care setting, a palliative day-care centre from an adjacent region was also included.

Criteria for participant inclusion were:

- ❖ Patients being admitted to one of the participating palliative care services;
- ❖ Physically and mentally capable to participate in the interview;
- ❖ Recently involved in a transfer between care settings.

Data collection process

Participant recruitment happened with the assistance of the coordinators of each of the care settings (the PST and PCU coordinators for the hospitals, the nursing home coordinator, the PHCT coordinator for the home setting and the coordinator of the palliative day-care centre). These coordinators were informed about the research project prior to their consent in assisting with the sampling procedure. Subsequently, they informed patients about the study and questioned them about their willingness to participate. To capture patient experiences within each care setting, we selected 20 participants accordingly. Settings and participants are illustrated in *Figure 1*.

Twenty semi-structured interviews took place between December 2015 and February 2016, at a location of the participants' choosing. Interviews were conducted by the authors AD and LN, both master students, lasting approximately one hour. Each interview was audio-recorded and field notes were taken. Prior to data collection, an interview training was given by the principal author (FM), an experienced qualitative researcher. Feedback on the interview style was given by FM after the first interviews.

Interview guide

A topic guide was used, developed and reviewed by FM, AD, LN and PP. The guide consisted of open questions and prompts, focusing on the experiences pertaining to the decision to transfer to another care setting and the actual course of the transfer as well as the expectations about a future care setting and the role of the family physician (*Table 1*).

Data analysis

All interview recordings were transcribed verbatim. We performed a constant comparative approach to analyze data (33-35), using NVivo 12 software to support the analysis procedure. After reading the transcripts thoroughly, all interviews were coded by FM and MS, both experienced in qualitative research. To validate the analysis process, FM and MS independently coded the same three interviews, subsequently discussing and comparing preliminary codings for similarities and differences. An initial coding frame was constructed and modified after each discussion and upon reaching a consensus. This procedure was repeated for the remaining interviews, resulting in the further construction of the coding frame. Next, all codes were once again compared with regard to similarities and differences in order to create categories and subcategories. Throughout the analysis process, an inductive and iterative approach was used, in which interview transcripts and codings were compared. Finally, the interpretation of the results was discussed with the other research team members (PP, MD, LD) and a final thematic framework was agreed upon. Since three of the authors have experience in palliative care delivery, we continuously reflected upon the interview transcripts and the analysis process to ensure the analysis was a true reflection of the data. Illustrative quotes were selected by FM, approved by the research team and translated.

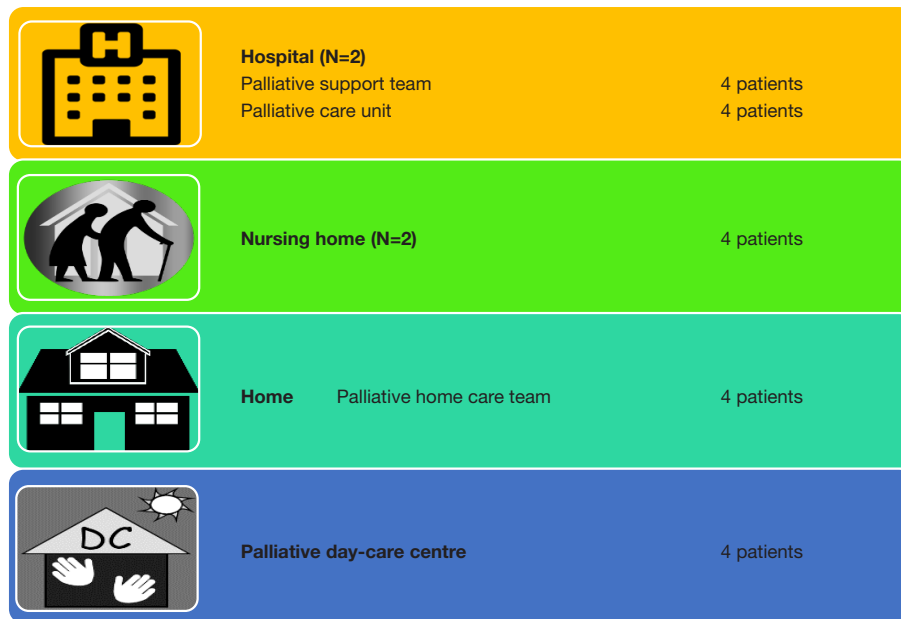


Figure 1 Settings and participants.

Table 1 Topic guide of the interviews

Topics	Guiding questions
Transfer decision	<ul style="list-style-type: none"> • Which problems provoked the transfer? • Why a transfer to that care setting? • Who took the decision? How did the decision process take place? Which professionals were involved? • How were you involved in the transfer decision? • What did you feel about the decision taken? • What did you feel about your involvement in the decision taken?
Course of the transfer	<ul style="list-style-type: none"> • How did you experience the transfer? • When you arrived, how were they aware of what you needed? • How did you experience your stay? • What were the differences compared to this setting? How did you experience this? • How did they take into account your emotional needs and physical problems? • What has changed since your return? • Are you still in contact with nurses/doctors/other care professionals where you resided? Is that something you would like/expect?
Future care setting	<ul style="list-style-type: none"> • What does your future look like? • Why will you be transferred to that setting? • What will be different there, do you think?
Role of the family physician	<ul style="list-style-type: none"> • Please tell me about your family physician • Which role does your family physician play in the care provided to you? • What is the relationship with your family physician?

Table 2 Sample characteristics

Participant number	Setting of recruitment	M/F	Age (years)	Pathology	Residence	Family status
P1	PDC	F	47	Non-cancer (chronic bronchitis)	Home	Single
P2	PDC	M	64	Cancer (intestinal)	Home	Single with children (ext)
P3	PDC	F	86	Cancer (leukaemia)	Home	Single with informal caregiver (ext)
P4	PDC	M	72	Cancer (intestinal)	Home	Cohabiting partner
P5	Home	F	41	Cancer (intestinal)	Home	Single with little children
P6	Home	M	65	Cancer	Home	Cohabiting partner
P7	Home	M	61	Cancer	Home	Cohabiting partner
P8	Home	M	45	Cancer (oesophagus)	Home	Cohabiting partner
P9	PCU	F	85	Cancer	PCU	Single with children
P10	PCU	M	64	Cancer	PCU	Single
P11	PCU	F	42	Cancer (intestinal)	PCU	Unknown
P12	PCU	F	46	Cancer (breast)	PCU	Unknown
P13	Hospital	F	61	Cancer (pancreas)	Home	Single with children
P14	Hospital	M	43	Cancer	Home	Single with children
P15	Hospital	M	67	Cancer	Home	Cohabiting partner
P16	Hospital	F	45	Cancer (breast)	Home	Cohabiting partner
P17	Nursing home	F	89	Non-cancer (frailty)	Nursing home	Widow with children
P18	Nursing home	M	94	Non-cancer (chronic bronchitis)	Nursing home	Partner with dementia—in nursing home
P19	Nursing home	F	97	Non-cancer (chronic kidney insufficiency)	Nursing home	Widow with children
P20	Nursing home	F	86	Non-cancer (cardiac failure)	Nursing home	Widow with children

PDC, Palliative Day-care Centre; PCU, Palliative Care Unit.

Ethical considerations

Ethical approval was obtained from the committee of the University Hospital in Ghent and AZ Delta Hospital in Roeselare (Nos. B670201524155, B670201524162, B117201523255 and B8117201523254). Participants were informed both orally and in writing about the study's objectives and about data anonymity. Written informed consent was obtained. Interview transcripts were provided with a number. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013).

Results

Twenty patients participated in this study. The recruitment

process was a difficult one, influenced not only by the patients' condition but also by the fear of upsetting participants due to the connotation attributed to the word 'palliative'.

Patient characteristics

Sample characteristics are displayed in *Table 2*. Of the 20 patients, 11 were female. Their mean age was 65 years, ranging between 41 and 97 years. Fifteen patients had cancer as the main pathology. Four patients resided at the palliative care unit, four others in the nursing home, while the remaining twelve lived at home. In total, eleven patients were single. Six out of the 12 home-residing patients had a co-habiting partner. Eight patients had children. The family status of two patients was unknown.

Main findings

In general, participants underwent multiple transfers across settings throughout their illness trajectory. Both the nursing home and the palliative care unit were considered the last residence, whereas back-and-forth transfers to the hospital were considered temporary. Interviewees accepted a transfer as a necessity, speaking in significantly less detail about it than their illness experiences and how settings had responded to their needs and expectations.

Participants' answers to the research questions resulted in three main themes: (I) experiencing the home situation: between preference and pragmatism, (II) perceived setting responses to patients' needs and (III) expectations towards the treating family physician in guiding the transfer.

Experiencing the home situation: between preference and pragmatism

Home was considered a familiar place. Although illness caused limitations in the functioning of day-to-day life, patients expressed their preference to stay at home, with or without the support of informal or professional caregivers.

Despite being the preferred residence, perceptions of feeling unsafe or insecure arose in the following situations: increased symptom burden, decreased activity of daily living (ADL), care organization insufficiently aligned to patients' needs or the absence or insufficient capacity of informal caregivers. Participants described how feelings of discomfort gradually arose: e.g., being alone at night with fear of sudden symptom crises; the fear, during the day, that something might happen after the nurse had left; the inability to fetch a glass of water when feeling thirsty, etc.:

'We asked for the nurse to come. However, in the end you experience that it's not sufficient, you know. Because in the afternoon, when you're not seeing anybody, and something happens, what do you need to do then? You can't just ring a bell er... And also the fact that they [the nurses] didn't find the house a couple of times, then you ask yourself "what are we just trying to do here"... [silence]' (P10, M, 64y)

'I was dying of thirst and over there, just around the corner, is the water – however, the distance was much too large, you know – although it was not far at all' (P13, F, 61y)

For people residing at home, the possibility of regularly visiting the palliative day-care centre was considered an added value, allowing them to forget their troubles temporarily and filling in lonely gaps by providing company, distraction and protection:

'At home, well yes, you're alone a lot of time, right? And

over there you aren't alone, you see. Over there, there's always somebody, you know... Yes, you can chat about all sorts of things, you can play board games or cards or do craft work or just relax and do nothing or...' (P1, F, 47y)

In the event of an acute increase of symptoms, a temporary transfer to the hospital was perceived to guarantee safety as well as immediate and continuous aid:

'P: I am pretty realistic. You can say, yes, I don't want to go to the hospital. But that is just a pointless thought. Obviously, everybody prefers to stay at home..., but the perspective of redemption was then a great relief to me... the sudden inability to breathe...'

I: So you somehow consider the hospital representing better care?

P: Maybe, I don't know. How should I say it: 'Immediate care.' I mean, if you're at home, lying in bed, tossing and turning due to the damn pain... I can't ring a bell here, and have a nurse around the corner saying 'I'll call the doctor and we can give you this or that product' and then the pain goes away. If that happens at home, it all takes a lot longer. That's what worries me.' (P13, F, 61y)

When patients' care needs became too extensive and informal caregivers could no longer address these needs, a more permanent transfer to the palliative care unit for terminally ill patients or to the nursing home for the elderly participants was the logical next step:

I: Who decided you were to come here then (nursing home)?

P: Myself... I was scared... to be alone... I couldn't go to the toilet on my own. I couldn't do anything.

I: Were you already bound to your wheelchair then?

P: At home, yes, yes. If I had to go to the toilet, then by wheelchair up to the toilet seat. They had to pull me onto it.

I: It was your husband who helped you at the time?

P: Yes. It was tough for him also, you know.' (P 20, F, 86y)

Although home was the preferred residence, for some patients it was not necessarily considered the preferred place to die. Determining factors in this regard were: the perceived added value of staying at home, the patient's sense of dignity and the informal caregivers' capacities:

'So, I think that I, as long as I am OK – well in the sense that I am not a burden to my family – and that, psychologically, I am still myself. Let me tell you: they can put me in a wheelchair, but don't take away my dignity, my personality. As long as I can keep my personality I will stay at home as long as possible – if it's feasible. You know, I am not the only person here at home.' (P8, M, 45y)

Perceived care setting responses to patients' needs

Patients reported mixed experiences of how care settings

responded to their needs.

Within the home context, a number of facilities were available to support patients and family members: nursing care, domestic services and family assistance. The way these were implemented however, did not always fully meet patients' needs, e.g., the timing of the nursing care or the number of hours of family assistance:

'What happens is that you have to wait for the nurse to come – they don't have fixed hours you know. They have to squeeze you in. Nurses normally come in the mornings. But a quarter to 12 or 5 to 12 is still considered morning, isn't it?' (P8, M, 45y)

Those patients receiving additional support from the palliative home care team (PHCT) appreciated having regular contact with the specialized PHCT nurse and reported being relieved to have his/her phone number, knowing that this person could be reached 24/7 in case of needs, questions, or in case the family physician was unavailable:

'... I've got their number, I know I can reach them. Also, when you have a question regarding the pain killers, or for the nurse, you know you can call them if the family physician can't be reached. It's a relief knowing that you have a back-up if you're home and something happens.' (P5, F, 41y)

With respect to the nursing home and the palliative care unit, both were regarded as the last residence, even though death was not imminent for nursing home patients. The latter regarded the nursing home as a home substitute with additional safety and good care. Those patients being transferred to the palliative care unit reported to perceive a maximum feeling of safety and comfort, being treated by pro-active personnel who took ample time for care and a good talk:

'It is super here, really, there is nothing to comment upon... You know, here, they've got time. You don't have to ask anything yourself, they themselves come to you asking if they can do something for you. Really, I feel at home here... And you know, they are such warm people. And somehow, they make you to start talking. I already had many good conversations here.' (P11, F, 42y)

These setting experiences contrasted sharply against those of the hospital, in the event of a temporary hospital admission. Patients spoke about acute symptoms (e.g., acute pain, bleeding, shortage of breath, fever, ...) or progressive deterioration (loss of appetite, loss of weight, mobility problems, ...) provoking the hospital admission. Whereas certain patients were positive about how they were treated, others explained that their experiences did not match their expectations. Firstly, interviewees reported health personnel to sometimes be insufficiently informed about their medical

history, even though they were certain this was registered in their electronic health record. Some patients experienced shortcomings in the inter-professional communication, resulting in the wrong medication being given and thus insufficient symptom control:

'I was racked with pain... And in the end it seemed that they [the nurses] had misunderstood... and I asked the doctor: "how come that I am still in pain?" "But yes, they did the opposite of what I told them to do."' (P7, M, 61y)

Secondly, patients reported to receive conflicting information regarding treatment options, such as whether or not to perform surgery. Thirdly, patients' experiences varied depending on the hospital or the hospital ward. For example, cancer patients admitted to the oncology ward felt being treated more humanely (personnel took time for the patient, was perceived to be informed about the patient's condition and delivered tailored care) than when admitted to other, non-oncology wards for non-cancer related problems:

'I've always been satisfied with hospital X: if you were in pain and you called for a nurse, they would always come and look for a solution. By contrast hospital Y, but well yeah – that was the ward of abdominal surgery – over there, it was very busy for the nurses – I needed to be given a painkiller at a certain hour – I had quite a lot of pain at that moment – and when I called the nurse, they said: "we're doing patient rounds now. We've started in the other corridor – we'll visit room per room until we reach yours." It took them more than an hour. So, yes, that makes you feel like a number. They don't think per patient, they're just acting room per room...' (P5, F, 41y)

Fourthly, patients' experiences differed depending the cancer type. For example, support for breast cancer patients, consisting of a care coordinating breast cancer nurse and various supportive facilities, differed significantly compared to limited support for pancreas cancer patients:

'We were in a group of 12 people, of which 8 with breast cancer. And that's when we saw daylight, because we were really unaware. Like, "Didn't you get this?" and "Didn't they tell you?" And you know, week after week there seemed to be all sorts of initiatives we weren't informed about. Really. You had to figure it all out yourself. Everything. And they themselves had the feeling to be overloaded at certain moments; like "Please leave us in peace for a while – with all those services that aren't beneficial to us at the moment". This was a real eye opener. So, yes, you ask yourself: how can this be? That's two-speed medicine, isn't it?' (P13, F, 61y)

With respect to the timing of hospital discharge, patients sometimes felt too weak and therefore unfit to return home. Furthermore, discharge experiences ranged from "well-

organized" to "inadequate" and "inefficiently organized with a lack of seamless care". As a result, some patients were obliged to organize themselves, depending their needs:

'On Wednesday they told me that I would be discharged the next day. I didn't feel at all ready, but hey, they probably needed the bed... And then, on Thursday morning... the doctor walks in and says: "We will do some more investigations this afternoon." And I say: "Hold on. They told me yesterday that I can go home today." "Well, that's not correct." So, I wasn't allowed to go home after all... And yes, on Tuesday, the week after, I finally went home. The discharge papers weren't entirely in order either. The speech therapist had to come, but the voice test hadn't been performed yet. The physiotherapist had to come, but something else hadn't been done yet. The nurse had to come, but some other things still needed to be taken care of first. The paperwork about my next appointment with the doctor was missing too. Anyway, all such things... And when you called: "Ah, we don't know anything about that." In the end, we organized all these things ourselves... But I have to admit that was the first time we experienced this.' (P8, M, 45y)

Expectations towards the treating family physician in guiding the transfer

Patients expressed mixed views on role assignment, expectations and experiences with respect to their family physician.

The role assigned to the family physician varied greatly among patients. For some, the family physician took on a central role—a counsellor, fully involved; to others a rather background role—available on demand; while to a few patients a minimal role – an insignificant position:

I: who did you talk to about coming home?

P: well eh, to the doctors involved, but also to the family physician of course, who played a central role at the time.' (P6, M, 65y)

I: I heard you say that your family physician was not involved... Did she play any role at all during the process?

P: Actually not. I took all the decisions myself. That's just the way I am. I want to do everything on my own.

I: And at the moment of the diagnosis, years ago, was she involved then?

P: No, actually not. I did what I wanted and also knew exactly what I wanted... I did go there a few times. And she told me then that I could always drop by for a chat – but, you know, I wouldn't know what to tell her. I don't feel the need to do so. I don't have a bond with her.' (P12, F, 46y)

The majority of the patients expected to be involved in the decision for a hospital referral and to be sufficiently informed about the reason for hospitalization. Furthermore,

they expected their family physician to be informed about the changes in patient's medical record and to guarantee care continuation after discharge. Patients were grateful towards their family physicians' hospital visit, although they especially expected them to be there for advice and assistance after hospital discharge:

'When you're in the hospital, you expect the specialist to be assisting you and when you're home the family physician...' (P10, M, 64y)

Patients hereby appreciated a regular home visit or the physician's initiative to inquire about their condition. These expectations were fully met for some patients, whereas others expressed to be disappointed because the family physician did not take any initiative, despite their long-standing physician-patient relationship:

I: And when you came home, did you call him to let him know that you were back home?

P: Well yes, I had to call him for the prescriptions, you know...

I: And did he then drop by regularly, or only when you asked him to...

P: When I called him, yes. Aside from that, I didn't see him.

I: You didn't see him. And during your time at home, did he (family physician) play any role at all?

P: No, well no. I didn't see him.

I: Not even when you were at home?

P: No, no. That's what I was surprised about. (silence) I don't know if he has something against me or what it could be. I don't know.

I: But you seem to find that difficult, no?

P: Yes. That he didn't visit me is not the only thing – it's just not nice – someone you've known for 20 – 30 years... but I really could have a good chat with him. But hey... (silence) Yes, that was really tough for me.' (P10, M, 64y)

Notwithstanding the long-standing relationship with the family physician, some cancer patients indicated they would rather contact the oncologist for advice and assistance directly when something went wrong, thereby bypassing the family physician, assuming to get a referral anyhow.

Discussion

Main findings

This study examined the experiences of 20 palliative patients regarding their transfers between care settings. In answer to the research questions, three themes emerged: 'Experiencing the home situation: between preference and pragmatism', 'Perceived setting responses to patients' needs'

and 'Expectations towards the treating family physician in guiding the transfer'.

In answer to research question one, participants reported that home was their preferred place of long-term care. However, perceptions of feeling unsafe at home arose in cases of increased symptom burden or decreased ADL and when the organization of home care was insufficiently geared to the patient's needs. In addition, home was not necessarily regarded the preferred place to die. In answer to the second research question, some interviewees also regarded both the nursing home and the palliative care unit as a possible last residence, offering safety and good care when home residence became unfeasible. In case of temporary hospital admission, notable experiences were reported on how settings responded to patients' needs, sometimes not meeting their expectations, but varying significantly depending on the hospital, the type of ward and the reason for hospitalization. Perceived issues regarding hospital discharge were: premature release, lack of seamless care and home care insufficiently tailored to the patients' needs. Answering the third research question, the family physician's role assignment were wide-ranging: from a central role to one in the background or even a minimal one. Patients especially expected their family physician to ensure the continuity of care.

Comparison with existing literature

Previous research showed that most patients with an advanced illness prefer dying at home (13,36,37). Other studies reporting on preferences for place of death suggest that the perceived burden to others is one of the reasons for not choosing home as the preferred place to die (37,38). Cai *et al.* described variables determining the preference for home death for cancer patients (38). Apart from the perceived burden to caregivers, other variables determining this preference were the intensity of visits by a home-based physician and personal support worker, marital status, educational status and the palliative performance scale scores of patients (38). Reyniers *et al.* described the preference of dying in the hospital due to the lack of other options and the perception of the hospital as a safe haven at the end of life (39). Some patients in our study made a clear distinction between their preference for home residence and dying at home. Their expressed reasons for wishing not to die at home concerned existential factors (the loss of one's sense of dignity and the loss of the significance of being at home) and psychosocial factors (the feeling of burdening

caregivers, being alone or having insufficient caregiver support, the general lack of feeling safe). An important finding of this study is that although the majority of patients with an advanced illness prefer to die at home, patients sometimes change preferences depending on the feasibility of their context situation. These findings underline the importance for involved professionals to carry out a timely evaluation of patients' preferences and needs, in order to adapt the care organization and delivery accordingly (e.g., a temporary transfer to the palliative care unit to diminish the caregivers' burden, increase the frequency of visits by family physicians and/or the palliative home care team to positively influence symptom control, etc.).

Experiencing feeling safe (or not) was a recurring topic throughout our study results, associated with the changing care needs of the patients on the one hand and a possible transfer between care settings on the other. Previous literature reported on perceptions of safety and good care of patients when transferred to the palliative care unit or to a nursing home (24), which corresponded to our study results. Also, the feeling of safety and familiarity with the hospital setting have been described, being influential factors for seeking emergency department or acute hospital care in case of increased symptom burden in advanced cancer (40,41). Authors argued that this may be the result of patients being more familiar with hospital services after having extensive hospital contact during the illness trajectory and being less familiar with palliative care services in cases of late referral to palliative home care (40). Interviewees in our study too reported on the safety of the hospital environment, that guarantees immediate and continuous aid in situations of acute illness. However, those interviewees receiving support of the palliative home care team described a feeling of relief to have the phone number of the team, knowing a back-up is always available in case of need.

With respect to the family physicians' role in palliative home care, Beernaert *et al.* (42) described the broad range of roles of the family physician: a medical expert, a communicator, a collaborator and a life-long learner. Some of these tasks changed depending on the phases of the illness (e.g., at the time of diagnosis, during treatment or during follow-up), while others were applicable throughout the complete illness course (42). According to patients and relatives, in addition to these roles, essential characteristics of the family physician involved in high-quality palliative care at home include his/her medical proficiency; availability; a person-centered approach; collaborative, informative and communicative nature (including with

other professionals); and proactivity (43). Patients in our study generally appreciated the family physician's involvement. However, some interviewees expected more involvement than others. Our study results confirm that the roles attributed to the family physician change throughout the illness trajectory. Noteworthy is that some participants indicated to be disappointed when the family physician lacked a pro-active attitude. The above-mentioned findings highlight the importance of an early involvement of both palliative home care and the family physician during a patient's illness trajectory. Furthermore, family physicians should be aware that patients' expectations towards their involvement (both in subject and in degree of involvement) can change throughout the illness course. It is therefore recommended that these expectations be openly evaluated and agreed upon during physician-patient meetings.

Although a feeling of safety and familiarity with the hospital have been reported, palliative patients are vulnerable to experiencing problems of care fragmentation and poor care quality during transfers between care settings (8). Poorly executed patient transfers between palliative care settings are often associated with miscommunication (both inter-professional and provider-patient communication), insufficient information exchange, insufficient collaboration between care professionals and a disruption in the continuity of care (8,11,22-44). Our study results corroborate these findings and moreover illustrate that the delivered care, especially within and between hospital and home care settings, was not always tailored to the needs of the patients (e.g., symptom management during hospitalization, timing of hospital discharge, organization of home care).

A last topic to discuss concerns the difficulty of patient recruitment in palliative care research. In our study, the recruitment process was hindered due to patients' bad condition (patients being too weak and ill to be interviewed), particularly those patients residing at the PCU. Furthermore, the fear of upsetting patients due to the connotation ascribed to the word 'palliative', hampered the participant recruitment. This happened especially in the hospital, with respect to patients recruited through the PST. Earlier research reported on the challenges of patient and family carers' recruitment in palliative care research due to professionals' concerns about the vulnerability of the patient or the fear of provoking possible anxiety or upsetting patients and families, being a reason for not approaching eligible patients (45-47). Aoun *et al.* furthermore conclude that strategies that facilitate health professionals'

understanding of the research and risk and benefits may help reduce gatekeeping in palliative care research (45).

Implications for practice and policy

Although patients in our study reported home to be the preferred place of care, the safety issue determined the feasibility of staying at home. Given the rapidly changing nature of life limiting conditions, caregivers and community services are challenged to respond in a timely manner to meet the needs of the patient and to ensure patient's safety. Considering the complexity of palliative patients' needs, more attention should be paid to organize care in a manner tailored to the specific needs of patients. The question hereby is not only if the current spectrum and quantity of available palliative care services are able to meet the actual needs of patients but also how palliative care services and healthcare professionals involved can collaborate efficiently and effectively to provide high quality care across settings. Integrated palliative care focuses on coordinating care around the needs of patients with advanced illnesses and has been increasingly put forward to achieve continuity of care for patients with life limiting conditions (9,48).

Strengths and limitations

All types of palliative care settings of the region were represented in this study. Together with the choice of a qualitative research approach, this resulted in a broad perspective on patients' viewpoints on the topic. However, a limitation may be attributed to participant recruitment in the hospital. The concern of upsetting patients because of the connotation of the word 'palliative' may have resulted in a greater participation of patients that approached the end-of-life stage of their illness trajectory. We do not know to what extent these viewpoints differ from patients of an earlier palliative phase.

Insights of this study may inspire other palliative care clinicians and researchers. However, we should be careful not to generalize the results, as the Belgian healthcare context and its palliative care organization may be too specific, even though similar organization of palliative care exist throughout other European countries.

Conclusions

Our study results confirmed that home is the preferred

place of care, as long as it is perceived a safe environment. Next, patients sometimes change preferences depending on the feasibility of their context situation. Furthermore, a person-centered approach that focuses on the complex needs of the patient rather than somatic aspects of care, has not yet been implemented throughout care settings involved in palliative care. Study findings illustrated shortcomings in inter-professional communication, care fragmentation and care coordination. As such, barriers in inter-professional collaboration need to be tackled to provide high quality care across settings, tailored to the needs of patients. Study findings highlight the importance of early involvement of palliative homecare and the involvement of the family physician in the illness trajectory. In addition, family physicians should be aware that the patients' expectations towards their involvement can change throughout the illness course. Accordingly, it is recommended that physicians take the initiative to openly evaluate these expectations with their patients.

Interventions aiming at improving inter-professional collaboration and continuity of care for patients being transferred between settings should be further investigated. Clinicians and policy makers could use these insights to enhance tailored palliative care.

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Footnote

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The authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Ethical approval was obtained from the committee of the University Hospital in Ghent and AZ Delta Hospital in Roeselare (Nos. B670201524155, B670201524162, B117201523255 and B8117201523254). Written informed consent was obtained. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013).

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