



Family carers' experiences regarding patient transfers between care settings in palliative care: an interview study

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Background: To understand how family carers experienced the illness trajectory of their next of kin related to transfers taken place between care settings in palliative care, their experiences and attitude regarding the transfer decision and their experiences regarding patient transfers across settings.

Methods: Semi-structured interviews were held with 21 family carers. A constant comparative approach was used to analyze data.

Results: Three themes were identified after data analysis: (I) patient transfer dynamics, (II) experiences regarding the changed care environment and (III) impact of the transfer on the family carer. The dynamics of the patient's transfer were affected by the balance between the care provision (professional and informal care) and the changes in the patient's needs. Experiences regarding patient transfers strongly varied depending on the setting and were based on the personnel's conduct and the quality of receiving information. Study results revealed shortcomings in perceived inter-professional communication and continuity of information during a patient's hospitalization. Concomitant feelings of relief, anxiety or feeling insecure could arise in situations of a patient's transfer.

Conclusions: This study highlighted the adaptability of family carers when caring for their next of kin with palliative care needs. To support carers in coping with their role as caregivers and to share the responsibility of caregiving, involved healthcare professionals should timely evaluate family carers' preferences and needs and adapt the care organization accordingly. A pro-active attitude, which anticipates on the possibility of an impending decompensation of the family carer, is recommended. When the decision for a patient's transfer is taken, multiple factors influenced the choice of the care setting. Healthcare professionals need to take these factors into account when discussing, with patients and carers, the need for a transfer. Continuity of information can be improved. Further development and evaluation of interventions, aimed at improving informational continuity can be recommended.

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

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Introduction

Family carers [definition: see Box 1 (1)] play a major role in caring for patients with palliative care needs (2). They provide emotional support, assist with practical tasks, help to relieve pain or other symptoms and aid in guiding patients through the healthcare and social services systems (3-5). In future, their role is becoming even more important given the fact that the majority of people with a non-curable life-limiting disease prefers to remain at home, as long as possible. Furthermore, the number of patients with complex palliative care needs increases in developed countries due to population ageing, a higher number of people living with chronic conditions and comorbidities, and improvements of disease treatment (6). Although caring for a person with a life-limiting illness can be rewarding, negative effects on the family carer at the physical (e.g., fatigue, older carers having their own health problems), psychosocial (e.g., anxiety, social isolation) and economic levels (medical expenses, working less or giving up work to provide care) have been described (1,7).

Seriously ill patients with palliative care needs often move between care settings due to a fluctuating burden of illness (8-10). These transfers can take place from hospital-based care to community-based care, or vice versa. Transfers

between care settings can be burdensome to patients and their families and pose a challenge on the continuity of patient care (11-14). Poorly executed transfers can be associated with delays in discharge and follow-up, miscommunication about follow-up and disruption of the continuity of care, which may result in higher rates of health care spending and service use (14-16). Importantly, strong continuity of care for patients with palliative care needs results in lower rates of emergency department visits, decreased hospital deaths and supportive needs being met (12).

Past studies have focused either on quantitatively assessing the frequency, types and reasons for transfers (9,17-19), or target specific patient groups, such as transfers of patients with cancer, heart failure or older patients (9,20-22). With respect to care settings, previous studies reported on palliative care transitions from acute care (inpatient hospitalization) to community-based care, but did not include other settings that deliver palliative care such as nursing homes and palliative care units (PCUs) (14,23). Similarly, other studies described patient and caregiver perceptions of continuity of care or health care providers' views on transfers from hospital care to palliative care at home (13,24). Studies reporting on the experiences of family carers regarding patient transfers across multiple care settings in palliative care, are scarce. We aimed to fill this gap, in order to identify areas of improvement in palliative care delivery and continuity of care during patient transfers.

In this study we aimed to understand how family carers experienced the illness trajectory of their next of kin related to transfers taken place, their experiences and attitude regarding the transfer decision and their perceptions regarding the patient's transfers across settings.

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) (25,26). 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 (27).

This study is part of a wider research project, aiming to optimize the continuity of care for patients with palliative care needs during transfers between care settings. The project concentrates on palliative care provided within one of the fifteen palliative care networks in Flanders, Belgium, exploring the experiences of healthcare professionals (28), patients (29) and family carers. This paper reports on the experiences and perceptions of family carers.

Highlight box

Key findings

- Patients' transfer dynamics were affected by the balance between the care provision and the patients' changing needs.
- Experiences varied depending on the setting and were based on the personnel's conduct and the quality of receiving information.
- Feelings of relief, anxiety or feeling insecure could arise in situations of patient transfers.

What is known and what is new?

- Family carers play a major role in caring for patients with palliative care needs.
- Studies reporting on family carers' experiences regarding patient transfers across palliative care settings, are scarce.

What is the implication, and what should change now?

- Healthcare professionals should timely evaluate family carers' preferences and needs and adapt the care organization accordingly.
- Multiple factors influenced the choice of the care setting during patient transfers. Healthcare professionals should take these into account.
- Developing and evaluating interventions, to improve communication and continuity of information, can be suggested for further research.

Box 1 Definition of family carer

In literature, the terms 'informal carers' and 'caregivers' are used interchangeably with 'carers'. For this study, we adopted the definition used in the European Association of Palliative Care-Task Force on Family Carers: "Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management" (1). They can live with or separately from the person receiving care and are as such a heterogeneous group.

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 (30), 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 (30).

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 (31,32).

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 (33). 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 (PST) and one inpatient palliative care service per 200,000 inhabitants, and one home care team per 100,000 inhabitants (34). 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 (34). 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 (34).

Palliative care in Flanders, Belgium (35,36)

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 PCU, consisting of 6–12 beds. The second is a PST, a multidisciplinary mobile team that provides second-line consultation to hospital staff with regard to palliative care management for patients not staying at the PCU. This article is presented in accordance with the COREQ (Consolidated Criteria for Reporting Qualitative Research) reporting checklist (37) (available at <https://apm.amegroups.com/article/view/10.21037/apm-23-20/rc>).

Methods

Design

A qualitative research design was chosen, using semi-structured interviews to deeply explore the experiences of family carers.

Settings and participants

The region researched, 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 PST and the largest hospital additionally has a PCU with 9 beds. All types of care settings within the palliative care network of the covered region were taken up in the research project: the home, the nursing home and the hospital, the latter of which included a PST and the PCU. The regional PHCT, two nursing homes and two hospitals were selected to participate in the research project. The largest hospital was chosen, since it was the only one in the region with a PCU while the selection of the second hospital occurred because it had the largest number of patients receiving PST support. The selection of the nursing homes was based on size (largest).

Recruitment of family carers

Participant recruitment took place with the assistance of the respective coordinators of the PHCT, nursing homes and hospitals' PCU and PST. Inclusion criteria were: being a close family member of patients recently admitted to one of the participating palliative care services, as well as being involved in a transfer between care settings. Attention was

paid to recruiting family carers from each of the different care settings providing palliative care, to capture as broad a range of experiences as possible.

Data collection process

Interviews were conducted with the assistance of two students of Master of Science in Health Care Management and Policy. 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 initial interviews. All interviews took place between April and May 2016, at a location of the participant's choice and lasted about approximately one hour. Each interview was audio-recorded and field notes were taken.

Interview guide

A topic guide was developed, used and reviewed by FM and PP. The guide consisted of open questions and prompts, focusing on the experiences of family carers with respect to the decision for the patient's transfer, the course of the transfer, the communication with healthcare professionals, care changes after transfer and the impact of the transfer on the relationship with the patient (*Table 1*).

Data analysis

All interviews were transcribed verbatim. A constant comparative approach was used to analyze the data (38,39). First, to familiarize themselves with the data, all transcripts were read thoroughly by FM and SV, both experienced in qualitative research. Next, FM and SV independently coded the same three transcripts, to validate the analysis process. Subsequently, preliminary codings were discussed one by one and compared for similarities and differences. An initial coding framework was constructed and modified after each discussion and upon reaching a consensus. Until the 10th interview we followed the identical procedure, first coding independently and then discussing the codings, comparing them for similarities and differences and finally further constructing of the coding frame. For the remaining interviews, only the differences were discussed after independent coding by both FM and SV and after FM compared the codings. Next, all codes in the coding framework were compared again with regard to similarities and differences and grouped into categories

Table 1 Topic guide of the interviews

Topics	Guiding questions
Illness trajectory	<ul style="list-style-type: none"> • What is the current situation of your next of kin? (if still alive) • How did you experience the illness of your next of kin?
Transfer decision	<ul style="list-style-type: none"> • Which problems provoked the transfer? • Who took the decision for the transfer? Who was involved? • How did you feel about the decision of the transfer?
Course of the transfer	<ul style="list-style-type: none"> • How did you experience the transfer procedure? • With whom (healthcare professionals) did you communicate? How did you experience this communication? • Did you feel adequately informed regarding your next of kin's condition?
Care after transfer	<ul style="list-style-type: none"> • What has changed after the transfer? How did you experience this?
Relationship with next of kin	<ul style="list-style-type: none"> • Did you experience changes in the relationship with your next of kin?

and subcategories. An inductive and iterative approach was used throughout the analysis process, hereby comparing interview transcripts and codings. Finally, the interpretation of the results was discussed with the other members of the research team (PP, MD, LD) and a final thematic framework was agreed upon. Reflexivity aspects were taken into account throughout the analysis process. We used NVivo 12 software to store the transcripts, to assist with the analysis process and to search for the quotes.

Ethical considerations

The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). Ethical approval was obtained by the committee of the University Hospital in Ghent, AZ Delta Hospital in Roeselare and Sint Jozef Hospital in Izegem (Nos. B670201525299, B670201525070, and B117201525245). Participants were provided with oral and written information about the objectives of the study and informed about the anonymity of the data. Written informed consent was requested and obtained, prior to the interviews.

Results

Twenty-one family carers were interviewed. In two cases, joint interviews were carried out with 2 family carers. Out of 21 participants, 5 were male. Their mean age was 58 (ranging between 26 and 76). Regarding relations: 3 participants were the patients' son, 8 the daughter or 2 the

daughter-in-law, 1 the sister, 1 the mother, 2 the husband and 4 the wife or partner. For 7 participants, the patient had died at the moment of the interview. An overview of participant characteristics is given in *Table 2*.

Although family carers were asked to recall and elaborate on the experiences of the patient's last care setting transfer, all interviews spontaneously brought back memories of the experiences of multiple transfers during the patient's illness trajectory. Data analysis identified three main themes related to the experiences of family carers and care setting transfers: (A) patient transfer dynamics, (B) experiences regarding the changed care environment and (C) impact of the transfer on the family carer. These themes will be addressed one by one.

Patient transfer dynamics

Family carers' experiences illustrated the complex dynamics of the events surrounding the patient's transfer. Below, we will elaborate on elements that make up the transfer dynamics: (I) care provision, (II) changes in patient's needs and influence on professional care, (III) transfer process and (IV) influencing factors regarding the choice of the care setting.

(I) Care provision.

During the illness trajectory of the patient, carers displayed a high degree of adaptability to provide them practical and emotional support, constantly evaluating and modifying priorities to meet the patients' changing needs. A carer's ability to provide care was influenced by

Table 2 Characteristics of participating family carers

Interview number	Setting of recruitment	M/F	Age (years)	Relation to the palliative patient	Patient pathology	Patient deceased?
1	Nursing home	M	52	Son	Dementia	No
2	Nursing home	F	45	Daughter	Dementia	No
3	Nursing home	F-F	67–71	Daughters	Heart failure	No
4	Nursing home	F	47	Daughter	Chronic bronchitis and mobility impairment	No
5	Nursing home	F	47	Daughter-in-law	Stroke and mobility impairment	No
6	PHCT	F	49	Wife	Cancer (intestinal)	No
7	PHCT	F	59	Wife	Multiple myeloma	Yes
8	PHCT	M	67	Husband	Cancer (oesophagus)	No
9	PHCT	F	66	Daughter-in-law	Cancer	Yes
10	PCU	M	56	Son	Cancer (prostate)	No
11	PST	M	72	Husband	Cancer	No
12	PCU	M	64	Son	Cancer (prostate)	Yes
13	PCU	F	64	Daughter	Cancer (breast)	No
14	PCU	F-F	26–51	Daughter-sister	Cancer (intestinal)	Yes
15	PCU	F	76	Mother	Cancer (intestinal)	Yes
16	PST	F	68	Partner	Cancer (lung)	No
17	PST	F	64	Wife	Cancer (sinus)	No
18	PST	F	55	Daughter	Cancer (cholangiocarcinoma)	Yes
19	PST	F	43	Daughter	Cancer (bone)	Yes

M, male; F, female; PHCT, palliative home care team; PCU, palliative care unit; PST, palliative support team.

the extent in which daily life could be reorganized in order to better support the patient, and also by the additional external support received. For the sake of the patient, they diminished or cancelled their social activities and hobbies and reorganized their domestic and professional responsibilities. Responsibilities towards the patient's care were often shared among family members (e.g., the spouse, children or siblings), resulting in an entire network of family carers. Non-resident family carers reported that the presence of the patient's spouse and the spouse's condition contributed to the possibility that the patient remained at home:

'Actually, we were lucky that our father was still in such good shape, that he took care of so much... Also to help her [mother] get out of her bed... I'm telling you, yes, for the rest, we did as much as we could, but after all, because we also have to go to work, it ended up mainly being dad...' (I19, F, 43y)

With respect to how caregiving was experienced, family

carers declared to take the patient's wishes into account as often as possible, however they sometimes felt walking a fine line between supporting and meddling, being squeezed between respecting the patient's autonomy and taking decisions for the patient's sake. Furthermore, carers often felt having to juggle between care for the patient and for their own family. Some participants reported a 'sandwich-experience' in care provision:

'Every morning someone of the domestic service did come by. But still, it's more than that... in the weekend you still had to go. And before we had additional help, I already did a lot... It was a difficult period, also having kids of your own... You have to compromise, you know... I still have an 11-year-old little girl, the other one is 16. It was like: the young ones need me, but you always feel the urge to go see your parents, to see if they're OK...' (I2, F, 45y)

The carer's capacity for caregiving was stretched further if having to deal with his or her own medical problems and/

or having to care for multiple family members. Conversely, family carers felt encouraged by the support of friends, neighbors and others with common experiences and concerns. The work context and interaction with colleagues formed a welcome distraction. Employers who showed an understanding for the carer's personal situation and allowed for flexible working hours were highly appreciated and were considered very supportive:

'I was lucky to have a good boss—my boss had also lost his wife due to cancer—and he was very understanding. He told me: "Take as many days as you need, I know what it means. We'll fix it..." And also at the time, there was a young couple living next door, they just moved in... And every evening after work, I first went to the hospital. When I got home around nine, the lady next door and also her husband, by the time I had parked my car in the garage, were standing here with some dinner, so I didn't have to cook myself. I mean, a young couple, I hadn't expected that. I told them: "You don't have to do this." She replied: "Whether I cook a potato more or less doesn't make a difference." I really appreciated that... It really felt good, you know. During that whole period, I had a lot of people supporting and helping me.' (IC8, M, 67y)

Being able to rely on the additional support of professional home care (e.g., a community nurse, a PHCT nurse and domestic care) resulted in a feeling of not being alone in the care process. Regular contacts and home visits by a PHCT nurse were highly valued for pain and symptom management and for mental support towards both the patient and the family carer. PHCT nurses were perceived to anticipate and to follow-up, but also to be very approachable, always at hand and willing to listen:

'You get the feeling that you are not on your own... because you can always count on those people if you have questions and they're always available, you can always call them if something is wrong.' (I6, F, 49y)

Furthermore, carers felt supported when the family physician conducted regular home visits after the patient's hospital discharge, when maintaining contact with the treating specialist, and when being approachable and taking time for queries or in situations of increased symptoms.

(II) Changes in patient's needs and influence on professional care.

For home residing patients with gradually changing needs, carers arranged for additional professional homecare (e.g., a community nurse, a PHCT nurse, cleaning or domestic services) or modifications to the house (e.g., a stairlift). In addition, the possibility of regularly visiting

a (palliative) day-care centre was a solution for care-dependent patients and for those family carers requiring respite care or who were still working:

'She actually increasingly needed help ... also due the fact that she became afraid of being alone. She had fallen a couple of times and didn't feel confident anymore... In the evening, the nurse came to put her to bed, and she stayed there until the nurse came back in the morning to help her out of her bed. You really felt that she... didn't feel safe anymore, despite having a wheeled walker. She didn't cook anymore either... we went there every evening to make her sandwiches and things like that... And then in October, she was able to go to the nursing home. In the meantime, between June and October, every day, except on Sundays, she went to the day-care centre in order to not be alone all day since we went out to work. She was practically immobile then.' (I5, F, 47y)

On the other hand, acute changes in the patient's needs (e.g., due to a fever, shortage of breath, vomiting, pain, mobility disorders, complications after surgery, adverse effects of medication) called for a rapid shift in care delivery, which was not always feasible, effective or sufficient within a short time span. It resulted in a patient's transfer to the hospital when patients and family carers regarded home care provision to be insufficient and the hospital to be a better place to receive care. The quote below illustrates, however, that this transfer was not perceived as a matter of convenience, but rather as a necessity:

'Then he left [hospital admission], he was vomiting all the time... Well, knowing that he is best off there [in the hospital] ... At home, it just wasn't possible anymore. I never did let him go, like "well yes, you can do that at home also..." I let him go the moment that it really...' (I7, F, 59)

(III) Transfer process.

The patient transfer process refers to the conditions in which transfers took place, how the decisions for a transfer were taken and how these decisions were perceived by carers.

Transfers took place when an imbalance arose between the patient's care needs and the care that could be provided, either professionally or by the family carer. Both carers and patients expected better care and quality of life in the future setting. Transfers to a nursing home occurred, for example in situations of dementia or frailty. In case of imminent death, a transfer to the hospital or the PCU (either directly or indirectly through hospital admission) was organized. The quote below about a patient in the terminal phase of bone cancer describes a situation in which the care needs

became too high and the spouse's and other family carers' capacities were insufficient to guarantee homecare, despite a maximum in professional care and modifications to the house:

'In the meantime, we had a stairlift installed, the shower upstairs was completely adjusted... The nurses came three times per day, ... she also had a special chair to be able to sit in the shower... but, yeah, the moment you really no longer can stand up on your legs anymore... And always being in that bed to be washed... in the end it is different, also for our father, it's too much extra fuss for him, ... also because she [patient] herself said: "this isn't working anymore" and uhm not everything can be left up to our father; despite the fact that we did the laundry and dropped in as often as we could, and I also took care of the cooking...' (I19, F, 43y)

The family carer's fear to be confronted with the image of the deceased patient at home, was another reason to refer the patient to the PCU or the hospital, instead of remaining and dying at home.

Transfer decisions were taken by patients, family carers or professional caregivers, often in mutual agreement. The voice of the family carer was more prominent regarding transfers from home to the PCU or the nursing home in situations when the carer could not provide sufficient capacity. The following quote illustrates some considerations preceding such a decision, and depicts the decisive position of a spouse after an exhaustive episode of caregiving, her son respecting the decision of his mother:

'She said: "Well listen, I don't want to live with that image [deceased husband at home] because I simply won't be able to cope with it. And I can't take care of him. That's one thing." "And secondly, he's been sitting here in his armchair for so long, me having to pull all the weight..."- and she did everything for him, and she became... I certainly felt that she was tired. She said: "Look, I don't want him to come back home. It would be much better if he stays there [PCU]." I said: "Listen mother, it is your decision, I will respect it, but you seriously have to think about this." "But I don't have to think about this anymore".' (I10, M, 56y)

Additionally, the family physician, aware of the patient's condition and with whom patients and family carers had a longstanding relationship, was often regarded a confidant, playing a major role in supporting, informing and advising the patient and family carer, for instance whether or not to admit the patient to the PCU or the nursing home. In general, participants appreciated to having a say in the decision process to transfer, but one participant experienced the specialist's advice for a transfer to the PCU

as a salvation, knowing that the patient was no longer in a condition that allowed a return home.

'That was our salvation, because if she had to come back home, I wouldn't have known how to manage that. She was worn out. And yes, she wanted to, go home... that was her last straw of hope, you know. As long as you're home there is still hope... staying home a little more. She really couldn't anymore. At that moment, she was in such a condition, she was really drained. That's why I consider it was a salvation. It was a salvation by doctor Y who insisted: "Let them take care of you at the palliative care unit".' (IC15, F, 76y)

However, transfers did not always happen in harmonious agreement. One participant (son) spoke about transfers as several 'battles' he had to overcome: he had to hold off the specialist's advice to discharge his father from hospital (he was finished with treatment) until a transfer to the nursing home had been arranged; next, in the nursing home, he struggled to have his father's euthanasia request handled with the sense of urgency deserved; finally, he struggled against the nursing home to allow his father to transfer to the PCU in order to fulfill his euthanasia request:

'That was another battle won, so to speak, to be able to transfer him from the hospital to the nursing home... In fact, it was again a battle we won the moment he went from the nursing home to the palliative care unit. In a manner of speaking, these are all battles. It isn't a real war; you know – the war we fight is to be able to die.' (I12, M, 64y)

(IV) Influencing factors regarding the choice of the care setting.

Carers reported to be relieved when their loved one was given the possibility to reside at the place of their preference. In case of a decision taken for a patient's transfer away from home, multiple factors influenced the choice of the care setting: practical aspects, the patient's life expectancy and the perception towards the setting. First, concerns of a practical nature were: the waiting time to bridge before the patient could be transferred (e.g., to the nursing home or to the PCU), costs, accommodation types and facilities at the future setting (e.g., the concern of a well-equipped room and tasty meals in the nursing home). Family carers also attached importance to the travel distance for caring or visiting family and friends to the patient's home, nursing home or the PCU. Secondly, family carers paid attention to the life expectancy of the patient, which influenced the decision for a transfer to either the PCU or the nursing home. A third influencing factor was the perception towards the setting. For example, the perception of being in the familiar surroundings of the oncology

ward, resulted in a patient's choice to die at the oncology ward instead of being transferred to the PCU, which was entirely unfamiliar to the patient. There was also the fear of being confronted with dying people at the PCU, whereas the oncology ward was still regarded as a hospital ward. This is exemplified in the following quote of a family carer who expressed a huge relief when her dying mother could remain at the oncology ward instead of being transferred to the PCU:

I: you asked the oncologist: "mother is in familiar surroundings [the oncology ward]. Can't she stay here?" "Yes, I felt relieved", you tell me?

I10: Well yes, firstly a relief for our dad, because... he doesn't like to drive and if he needs to take a route that he's not used to ... And a sigh of relief for us all, after all, in an environment... in the meantime we were acquainted with the nurses. We could always count on them if anything happened... And also, if some question had to be asked to the oncologists... and we also thought, if you end up in the palliative care unit, will you still see the oncologists? What is the best way to contact them if something happens? And also the idea of "palliative" and a "palliative environment"... they are all people who... are dying... And maybe we were happy that she was in the hospital, ok, even if it was the oncology ward... But everyone there had their own room, and you didn't really see each other. Ok, you saw the family in the corridor, but those people themselves, you didn't really see them. And also, if we would have had to go to the palliative care unit and you are continuously confronted with people who are seriously ill as well, people who can die at any moment or something like that... I really don't know. Maybe a little bit scared too? (I19, F, 43y)

Experiences regarding the changed care environment

With respect to the changed care environment, both the expectations and experiences of the family carer varied, depending on the setting.

Regarding the carers' setting-specific expectations, the nursing home was considered to be a permanent residence, when home care had become unfeasible. However, it was viewed as a temporary stay after hospital discharge, allowing the patient to regain strength before returning home. The hospital, in turn, was expected to be the setting where patients received temporary help with respect to diagnosis and treatment. In contrast to the hospital ward, where returning home after treatment was still presumed possible,

the PCU was considered 'the final station' and confronted family carers with the patient's imminent death.

Carers expressed having mixed experiences pertaining to the patient's transfers and new care environment. They were determined by the setting's ambiance, the way they were treated by the staff members and the manner in which information was exchanged. Those participants who became acquainted with the PCU, expressed positive experiences because of the way they and the patient were welcomed and treated, within a domestic atmosphere. Carers appreciated the PCU staff taking time for the patient and the family, the personal care, the sense that 'there are no musts' and 'everything is possible' and all the efforts being taken to please the patient and the family carers:

'The humane reception, taking time to speak to us, not treating you like a number... I tell you: it's heaven on earth here... Immediately it became clear that nothing is required and everything is possible... If you are thirsty, you drink. If you aren't, you don't. If you have questions, ask. Whether they are personal, emotional or medical questions, just ask. We will try to answer, but you always get an answer and you don't have to wait a fortnight for one, you understand?' (I12, M, 64y)

Furthermore, participants appreciated that the patient still had the freedom to make trips or pay external visits. Carers reported that the personnel of the PCU were gifted in grief and bereavement support, making it possible to talk about difficult topics. This included their highly valued approach towards little children and how they helped to prepare them for the patient's imminent death. Although not all participants indicated to need this, they were very grateful that even after the patient's death, they received phone calls from the PCU staff, inquiring about the carer's situation.

Similar positive experiences were reported about the nursing home environment: the way the patient and the family were treated by the nursing home staff, the quality of communication and the way family carers were involved in care plan discussions and decisions. Furthermore, they appreciated the domestic atmosphere:

'She's taken well care of here... They come here at least once a week with cheese cubes and salami cubes, a glass of wine... and there's always something to do here. At the moment, she is not moving around, but she says she will as soon as she feels better. With her rollator walker... and then they will go and have a walk with her...' (I3, F-F, 67-71y)
'Also, once the transfer has happened [hospital admission from the nursing home], there is sufficient communication

to inform about how it is going and to follow up the situation, by e-mail or phone or even by dropping by. If we call the hospital, we inform the nursing home and vice versa. It actually goes really smoothly.’ (I5, F, 47y)

In the hospital context, positive experiences were expressed towards the oncology ward, where personnel was perceived to be more gentle, friendly and took more time compared to other hospital wards:

‘the oncology ward, treatment there is different. The doctors as well as the personnel are, I might dare say, more compassionate towards the patient... And the doctor’s visit is more in depth and calmer. It’s not like a quick in and out visit, asking if everything is well and off I go. No, they stay a little and have a chat. The treatment at that oncology ward is actually very, very good.’ (I15, F, 76y)

By contrast, rather negative experiences were reported about other departments, such as at the emergency department, where different caregivers kept continuing to ask questions, and where carers suffered of waiting long before something happened.

Depending on the hospital, mixed experiences were expressed with respect to the comfort and facilities present in the hospital room, flexibility regarding visiting hours, the personnel’s conduct and the information exchange. The experiences of how hospital staff treated family carers and patients ranged from very positive (e.g., allowing the patient to leave the hospital to attend a baby shower) to rather negative (e.g., unfriendly; the patient being treated callously). Carers also reported that attention was not always sufficiently paid to the patient (e.g., a vomiting patient who was given medication orally, the medication box left at the table together with the patient and recovered later, without checking whether or not it was empty).

The perceived inter-professional communication within and across hospitals was not always optimal. Examples include: difficulties with information exchange between hospitals regarding the patient’s results; the patient not being allowed to eat, yet receiving a tray of food; a presumed failing information flow between professionals about handling the alleviation of pain, resulting in patient discomfort:

‘they admitted her and put her on a drip... She was strictly prohibited to eat or drink. That’s what the specialist told me because I was there at that moment. And then, half an hour later, a tray of food is brought in. So you say to yourself: if it were somebody who didn’t know anything about it, they would have eaten it, you know... And also, she was in a lot of pain and the specialist told us that she shouldn’t be in

pain at all... He said: “If you feel pain, you have to come and tell me, because then we will start a syringe driver”. One night, I get there and she was in horrible pain... But the nurse said that she wasn’t allowed anything extra. By the time my brother arrived 3 hours later, they still hadn’t give her any painkiller yet... That shouldn’t happen, you know...’ (I4, F, 47y)

Family carers attached importance to being informed about the patient’s condition. To obtain information during the patient’s hospitalization, participants often had to take the initiative, which they sometimes found demanding. Some carers felt hesitant to ask questions, as they did not want to intrude on staff, while others expressed emotions of annoyance at the amount of effort to gain information. Their experiences with respect to acquiring information ranged from very positive with approachable physicians who took time for the patient and the family carer and provided clear and tailored information, to negative, when physicians were difficult to approach. One participant suggested more information would be received from the family physician than from the treating specialist or the hospital nurses:

I: And when you were in the hospital, with whom did you have contact?

V: Ah, nobody. If you didn’t go to the desk yourself, you wouldn’t know anything...

S: Nobody said anything... No! We ourselves asked to speak to the doctor when she was ill... They need to have time, you know...

V: They should make time for their patients, right?

S: You know, the GP would have given more information than them...’ (I3, F-F, 67-71y)

Impact of the transfer on the family carer

Although a patient’s transfer meant readapting and reorganizing life to combine patient visits with domestic responsibilities, work and even care for the other parent, participants especially expressed an emotional impact following the transfer.

The emotional impact of transfers on family carers was expressed as relief, anxiety, being concerned or feeling insecure. Participants reported being relieved to hand over the responsibility of care, particularly if it was perceived the patient was in good hands, receiving the right care at the right time. There was also a relief of being liberated of the fear that something could suddenly happen to the patient at home and that, in an endeavor to provide help, incorrect or harmful actions could be taken:

‘Actually, for us it was also a kind of relief. If there’s anything, she is never alone anymore... And if something happens – if she falls, the nurses are there... We can help too, but we don’t know, if she falls, are we picking her up the right way? ...Aren’t we causing more harm than good?’ (I5, F, 47)

Despite being confronted with the grief of imminent loss, the carer also felt relieved, knowing that the patient would receive the best possible care at the PCU.

For some participants, the relief of knowing that the patient was in good hands in the new setting resulted in an improved quality of sleep:

I: The periods that he was admitted to the hospital for a longer length of time, how did you experience this?

P: Some sort of peace of mind, because I knew they were taking care of him and he had everything he needed there... And also... I’m going to be selfish now... Then I dared to sleep for once... because I knew that he was not here, that nobody could call me... I’m not going to say that I slept well, that isn’t it, but differently, a healthier sleep probably. Being able to let go a little. Yes... I’ve have been very afraid at night... Scared to get up and find him...’ (I7, F, 59y)

Aside from feeling relieved, participants expressed feelings of anxiety as hospital discharge approached while the patient’s condition had insufficiently improved. Others were concerned about how long it would be, before facing a next transfer to the hospital. One participant felt insecure, doubting whether she had succeeded in caregiving, as her husband was readmitted to the hospital shortly after discharge:

‘Well, you’re happy that he’s going to be discharged and is coming home, but immediately you ask yourself: ‘Hopefully it will be a long time before he needs to be admitted again’. It already happened twice, and I tell you: it was a blow that it happened again only after one week. So, you ask yourself, am I not taking care of him well enough? But they told me, the doctor too: “you can’t help it, it’s G who is in such a weak condition. You really shouldn’t feel guilty, there is nothing you can do about it”.’ (I17, F, 64y)

Discussion

Main findings

This study aimed to understand how family carers experienced the illness trajectory of their next of kin with palliative care needs related to care setting transfers, their experiences and attitude regarding the transfer decision and

their perceptions regarding the patient’s transfers across settings. Three themes were identified after data analysis: (I) patient transfer dynamics, (II) experiences regarding the changed care environment and (III) impact of the transfer on the family carer. The dynamics of the patient’s transfer were affected by the balance between the care provision (both professional and informal care), on the one hand, and the changes in the patient’s needs, on the other. Family carers reported varying experiences regarding the changed care environment, depending on the setting and determined by, among others, how they were treated by the personnel and the quality of receiving information. Concomitant feelings of relief, anxiety or feeling insecure could arise in situations of a patient’s transfer.

Comparison with existing literature

Family carers displayed a high degree of versatility, constantly changing priorities to meet the needs of the patient. The carer’s capacity, however, needed to be distributed between care for the patient and other responsibilities (e.g., domestic and family duties, work) and was stretched further when having to deal with personal medical problems or having to care for multiple patients. These results correspond to the results of previous studies, that report on the high levels of responsibility taken up by family carers and in which their caregiving is considered a natural, dutiful act (40,41).

Aside from juggling between all these responsibilities, participants in our study also reported they arranged additional home care as the needs of the patients gradually changed. The additional support of domestic services, community nursing care, palliative home care team nurses and the family physician not only meant the patient’s needs were better met, but also resulted in carers not feeling alone in the care process. This finding is consistent with previous research, describing the substantial impact of professional support on the ability of family carers to cope with the role of caregiving and ease the burden of responsibility (41-43). Furthermore, it reveals the dual position of the family carer: providing support and requiring support, as family carers often enter this caregiving role with little or no knowledge or experience (7,44).

Next to the position of professional support, study results showed that other informal carers can play a considerable role too in supporting patients and family carers (e.g., neighbors). This relates to the concept of Compassionate Communities. In the last decade, there has been a growing

interest in the development of Compassionate Communities and Compassionate Cities, and their significance towards palliative home care. This public health approach to end-of-life care, promotes the motivation of communities to take more responsibility in their healthcare, improving the care of people at the end of life, in which community support and palliative care work hand in hand (45,46). This promising evolution may contribute to family carers' better coping with caregiving and to the continuity of palliative home care.

Our study results showed that the decision to transfer a patient occurred as a result of an imbalance between the patient's needs and the professional and informal care. Literature about transfers of patients with palliative care needs, describes some transfers as unavoidable or useful (e.g., in situations of maximum caring capacity or due to certain medical conditions that can only be managed at the hospital) (47). By contrast, other transfers—especially those between the home and the hospital at the end-of-life—can be regarded as potentially avoidable (e.g., due to the inadequate availability of community services) (48,49). Taking into account that most patients with palliative care needs prefer to remain and die at home in familiar surroundings (50-52), healthcare professionals are thus challenged to use a pro-active approach to prevent avoidable transfers. Five key strategies have been described that can help avoid hospitalizations at the end of life: (I) marking the approach of death and shifting the mindset, (II) being able to provide acute treatment and care at home, (III) holding anticipatory discussions and interventions to deal with expected severe problems, (IV) guiding and monitoring the patient and family in a holistic way throughout the illness trajectory and (V) ensuring continuity of treatment and care at home (48). Using this pro-active approach requires, amongst others, an early integration of palliative home care, a timely organization of advance care planning discussions and a healthcare professionals' agreement on shared care goals (53,54). Previous findings reporting on healthcare professionals experiences within this same research project, showed however a lack of open provider-patient communication, which hampered the timely communication of advance care planning and the early integration of palliative home care (28).

Although end-of-life care literature and health care policies focus on the home setting being the desirable place of terminal care and death (50-52), it is noteworthy that some family carers in our study clearly stated not being able to cope with, or live with, the image of the deceased patient

at home. This too was a reason for a patient's transfer, irrespective of the support of additional professional home care. This result raises questions about the topic of 'dying' in the current social context in Belgium. While historically, death and dying were a part of life and occurred within the family home, we can question whether or not people have become alienated from this natural event and may not know how to cope with it, preferring to obscure behind hospital or institutional walls (55).

A next result that merits attention is the factors influencing the choice of the care setting once the decision to transfer the patient had been taken. These were: practical considerations (e.g., the travel distance for visiting family and friends, costs), the life expectancy of the patient and the perceptions towards the new setting. Our study findings showed that some participants, when faced with the imminent death of the patient, were not yet familiar with the PCU. This was a reason to remain and die at the oncology ward instead of the PCU. This finding underlines the major responsibility of healthcare professionals involved, to timely discuss all options in organizing palliative care at the end of life, including a referral to a PCU. At the same time, professionals should be aware of the factors that influence the choice of setting, as described above.

With respect to the changed care environment, family carers in our study were satisfied with personnel conduct and the communication at nursing homes. Highly positive experiences were expressed towards the PCU, because of the personal care, the efforts taken to please the patient and family and to create comfortable circumstances for patients approaching the end of life. These findings are consistent with previous study results (2,56,57). This study revealed greatly varying experiences with respect to the hospital, however. The experiences depended on the hospital, the hospital ward and the reason for hospitalization. Although positive experiences have been reported, our findings illustrated a number of shortcomings in tailored patient care and informational continuity of care (the sharing of medical information across care providers and settings) which affected the quality of patient care. This finding is consistent with the study of Morey *et al.* in which patients and family carers experienced a lack of informational continuity between providers when receiving care in the hospital (13). Similarly, in a longitudinal qualitative study with patients and family carers in five European countries, this was found to be a weak point in care provision, suggesting the need for interventions to improve communication between teams within the hospital (12).

In case of a patient's transfer, carers in this study expressed feelings of relief, knowing that the patient was in good hands and received good care at the new setting. This relief resulted from a sincere fear of doing wrong during the caregiving trajectory and dying process. Furthermore, the fact that one of the participants spoke in terms of being 'selfish' and feeling relieved when her partner was admitted to the hospital illustrates the burden of caregiving for family carers. Another participant expressed to feel insecure and doubted if she had taken care well enough. This result is consistent with other study findings (7,41).

Strengths and limitations of the study

All care settings that provide palliative care, comparable to other developed countries, were represented in this study. The study specifically focused on palliative care provided in one regional palliative care network and included family carers who shared their experiences about the different care settings. Together with the choice for a qualitative research approach, this resulted in a broad perspective on family carers' viewpoints on the topic. Although the insights of this study may inspire other clinicians and researchers involved in palliative care, we should be cautious to generalize the results as we were not able to compare these insights to the experiences of family carers in other regions.

Additionally, with respect to participant recruitment, we do not know the total number of family carers approached for participation in this study or the number of persons that did not show interest in it.

Conclusions

This study highlighted the adaptability of family carers in the caregiving process of their next of kin with palliative care needs. To support carers in coping with their role as caregivers and to share the responsibility of caregiving, involved healthcare professionals should timely evaluate family carers' preferences and needs and adapt the care organization accordingly. A proactive attitude, which anticipates on the possibility of an impending decompensation of the family carer, is therefore recommended.

When the decision for a patient's transfer is taken, multiple factors influenced the choice of the care setting. We suggest that healthcare professionals take these factors into account when discussing, with patients and carers, the need for a transfer.

Experiences regarding patient transfers strongly varied depending on the setting and were based on the personnel's conduct and the quality of receiving information. Study results revealed shortcomings in perceived inter-professional communication and continuity of information during a patient's hospitalization. The development and evaluation of interventions, aimed at improving communication and continuity of information, can be suggested for further research.

Some participants were unfamiliar with the PCU. A topic for future research may be how patients and family carers are informed about the options for organizing palliative care, the way healthcare professionals discuss the different options and the timing of these discussions during the care trajectory of the patient.

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Footnote

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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. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). Ethical approval was obtained by the committee of the University Hospital in Ghent, AZ Delta Hospital in Roeselare and Sint Jozef Hospital in Izegem (Nos. B670201525299, B670201525070, and B117201525245). Participants were provided with oral and written information about the objectives of the study and informed about the anonymity of the data. Written informed consent was requested and obtained, prior to the interviews.

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