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Family members' experiences of psychosocial support in palliative care inpatient units: A descriptive qualitative study

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ABSTRACT

Purpose: The support for family members (FMs) during a patient's palliative hospital care has been rarely studied, creating a gap in how FMs can be better supported. Psychosocial support answers widely to FMs' needs. Therefore, this study aims to describe FMs' experiences of psychosocial support in specialist palliative care inpatient units from the perspective of the FMs themselves.

Methods: A qualitative descriptive study with individual semi-structured interviews and inductive content analysis was conducted. Data were collected in four specialist palliative care inpatient units in two large hospital districts in Finland. The 32-item checklist Consolidated Criteria for Reporting Qualitative Studies was used to ensure detailed reporting.

Results: A total of 19 FMs of cancer patients receiving palliative care participated in the study. Their experiences of psychosocial support focused on Support *FMs hoped for,* Support *practices in the care unit, and Informational* support *for FMs.*

Conclusions: According to FMs' experiences, support focusing particularly on the FMs, safe quality patient care, proper access to information regarding the patient's care and condition, and genuine encounters with HCPs were the aspects that seemed to be the most important to the FMs. Systematic provision of support and information should be a routine model in palliative care. Additionally, a care environment that promotes FMs' presence, participation, and family-centred care is essential in FMs' support and should be considered when developing family involvement in palliative care. Furthermore, the importance of FMs receiving sufficient information, and FMs' dependence on HCPs to share the needed information, should be acknowledged. Hence, more attention should be paid to successful information sharing between the HCPs and FMs in palliative hospital care.

1. Introduction

Palliative care is provided for around 50 million people annually, primarily for cancer patients. Family members (FMs) of the patients, i.e., people with close personal relationships with the patient, are affected by the patient's disease and therefore also need palliative care services (Connor, 2020). In high-quality palliative care, FMs are considered integral to care and receive support alongside the patient (Alam et al., 2020).

Support for FMs focuses on their ability to cope, and includes physical, emotional, social, spiritual, and informational support (Hui et al., 2021). Furthermore, psychosocial support consists of psychological elements broadly concerning FMs' spiritual, emotional, cultural, and social needs, but it can also involve more practical components like support regarding finances, housing, and daily living (Macleod, 2008).

Coping as a process was described as a theory by Lazarus and

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Folkman decades ago, and it has been widely utilised in research (Biggs et al., 2017). According to this theory, the coping process results in an adjustment due to cognitive appraisal (Lazarus and Folkman, 1984). During the process, problem- and emotion-focused coping strategies are used to manage stressors or regulate emotions (Lazarus and Folkman, 1984). This process and these coping strategies were incorporated into the design of this study.

FMs experience various support needs when they are trying to cope (Ullrich et al., 2017). In research on this subject, FMs' experiences of informational, emotional, and social needs have been emphasised, but physical, financial, service-related, and spiritual needs have also been reported (Wang et al., 2018). Although all severe illnesses are associated with the burden on FMs, palliative care and hospital settings considerably increase the need for support (Lee and Cha, 2017). Often, the support needs of FMs are not entirely met (Ullrich et al., 2021). Unmet needs can lead to anxiety, depression, and emotional distress, which elevate the risk for psychological morbidity (Grande et al., 2018), reduce physical health status, and worsen the quality of life (Choi and Seo, 2019). Hence, FMs need additional support in adjusting to palliative care situations (Lazarus and Folkman, 1984; Oechsle et al., 2019). FMs also need guidance and support in their involvement in hospital care, which can enhance the quality of the patient's care and increase the ability to cope for both patients and family members (Alam et al., 2020; Bélanger et al., 2018). Furthermore, FMs can provide the patient with emotional support and participate in practical care tasks and decision-making, which is also meaningful, particularly to the patients (Lemetti et al., 2020).

In hospitals, the healthcare personnel (HCPs) have a significant role in providing psychosocial support to FMs, especially emotional and informational support, although the support is not always optimal (LaValley, 2018). In this study, HCPs are described as paid persons working in hospitals directly involved with the palliative patient and family care, e.g., physicians, registered nurses, practical nurses, and therapists. Although they do not participate directly in patient care, social workers and pastors are also integral to palliative care teams (Saarto and Finne-Soveri, 2019). Psychological support, family-centredness, a comforting environment (Bainbridge et al., 2018), empathy on the part of HCPs, the opportunity to visit the patient freely, for example, without restrictions on visiting times (Donnelly et al., 2018; Virdun et al., 2017), and a welcoming atmosphere (Røen et al., 2018; Virdun et al., 2017) have been mentioned as elements of psychosocial support for FMs.

FMs often concentrate on caring for the patient's well-being while neglecting their own needs (Wang et al., 2018). Furthermore, FMs may not have enough information about the possibilities of receiving support (Oechsle et al., 2019; Ullrich et al., 2017). As a result, FMs can experience difficulties in their involvement in hospital care (Saarinen et al., 2021) and communication problems with HCPs, including limited information sharing, the unavailability or unapproachability of HCPs, and overall dissatisfaction with the hospital environment (Robinson et al., 2014).

Current studies about psychosocial support for FMs in palliative care mainly concentrate on home-based care (Areia et al., 2020; Soikkeli--Jalonen et al., 2021) with restricted generalisability to hospital settings (Ullrich et al., 2021); research on hospital care is limited. The palliative care hospital environment is different from other care settings regarding the burden and anxiety caused by the condition of the patient, but also because of the family's new role in an unfamiliar environment (Belayachi et al., 2014), communication between the HCPs and the family (Robinson et al., 2014; Ullrich et al., 2017), and the added stress of decision making and participation in the patient's care (Saarinen et al., 2021). Further, studies have rarely been conducted from the perspective of FMs, and knowledge about their in-depth support experiences in palliative hospital care is lacking (Hasson et al., 2020).

FMs experience hospital environments as unfamiliar and foreign, and they need psychosocial support in finding their own space and position and in adjusting to their role (Partanen et al., 2018; Ullrich et al., 2017). Additionally, some studies have focused on the unmet needs of FMs, but it is unclear how and by what means FMs perceive they are supported in hospitals (Ullrich et al., 2017, 2021; Wang et al., 2018). Therefore, this study aims to describe FMs' experiences of psychosocial support in specialist palliative care inpatient units.

2. Method

2.1. Study design

A qualitative descriptive study with semi-structured interviews was conducted to describe the psychosocial support experiences exclusively from the perspective of FMs.

2.2. Setting

The study was conducted in four specialist palliative care inpatient units in two large hospital districts covering about 40% of the Finnish population. Specialist palliative care can be defined as comprehensive care for patients and families in which HCPs have special expertise (Forbat et al., 2020). In Finland, specialist palliative care is implemented in care units where palliative care is the primary function (Saarto and Finne-Soveri, 2019).

2.3. Participants

Study participants were recruited with the help of a contact person from each unit and purposively sampled with the help of the nurses, who identified the informants who were most able to share their experiences without excessive burden. The inclusion criterion was that participants were adult ($\geq$18 years) Finnish-speaking FMs of palliative care cancer patients in a specialist palliative care unit. The patients whose FMs were to be interviewed also had to have incurable cancer, had to have received palliative hospital care for at least one week with only symptomatic treatment, and had to have agreed to the FMs' participation in the study. Before recruiting FMs, each patient's agreement was ensured by having them name a participating FM, who was then contacted. In total, the recruitment period lasted seven months, and all FMs who met the inclusion criteria and were willing to participate were included during the data gathering period. The data were collected until saturation was reached. Due to the long recruitment period and recruitment strategy implemented by contact persons and nurses, we do not have information about those who refused to participate.

2.4. Data gathering

Data gathering was conducted from May to November 2019. The patients and FMs were informed about the study aim, content, and procedure, and informed consent was requested before the interviews. The interviewers' professions, positions, and roles in the research project were also explained to the participants. Individual semi-structured interviews were conducted in a quiet room on each ward and were digitally recorded (Holloway, 2017). FMs were interviewed privately, without the patient, so that only an interviewer and the FM were in the room. The interviews were facilitated either by a female research assistant who worked as a palliative care nurse but had no care relationship or connection to the patient or by a female PhD candidate.

The data gathering was based on pre-defined themes from previous literature about the psychosocial support needs of FMs (Aoun et al., 2013, 2014, 2017; Beynon et al., 2014; Halkett et al., 2018; Harding et al., 2012; Hashemi et al., 2018; Papastavrou et al., 2012; Peters et al., 2015; Robinson et al., 2014; Wang et al., 2018). The themes were constructed according to the strategies of the coping theory (Lazarus and Folkman, 1984), as well as the core areas of psychosocial support (Macleod, 2008), including informational support (problem-focused

coping strategy) and emotional support (emotion-focused coping strategy). Participants were also asked to describe any other element of psychosocial support they had experienced. The interview questions followed the themes but were not precisely specified. For example, the interview included questions for the FM such as: "What informational/emotional/other support did you receive?" and "What informational/emotional/other support would you have hoped for?" Thus, the interviewer could conduct the interview freely within the themes. To describe the FMs' experiences and construct categories, the data gathering continued until code saturation was reached and when conducting more interviews was no longer considered to raise new perspectives regarding the FMs' support experiences. However, after that, a few more interviews were held to gain a deeper understanding of the contents of the categories, to better describe the phenomenon, and to ensure that all perspectives had been fully heard (Hennink et al., 2017). The duration of the interviews ranged between 13 min and 1 h 13 min (mean 33 min). The 32-item Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist was used to ensure detailed reporting (Tong et al., 2007). The interviewers' personal characteristics and relationship with the participants were considered to minimise personal bias (Table 1). The study design, including theoretical framework, participant selection, study setting, and data gathering, was developed and described following the checklist guidelines to include and report required elements concerning the qualitative study design. Additionally, the COREQ -checklist was followed during the data analysis and reporting of study findings to improve the credibility and trustworthiness of the study results.

Table 1
Family members experiences of psychosocial support.

Main categories	Categories	Sub-categories
Support FMs hoped for	FMs' opportunities to have supportive interactions	FMs' permanent care relationship with HCPs
		HCPs' empathic approach
		Peer support for FMs
	Support aimed at FMs	Automatic provision of support for FMs
		Support that takes FMs into account
Support practices in the care unit	FMs' support resources	FMs' self-acquired support
		Support organised by the care unit
	Supportive care environment	Competent and emphatic personnel
		FMs' experiences of the quality of the patient care
		FMs' opportunities to be present in care unit
		Inadequate support experiences
Informational support for FMs	FMs' informational needs	Information about practices in inpatient unit
		Guidance for finances and home care
		Automatic provision of information for FMs
		FMs' possibilities to limit the information
	Information contents	Information about patient care
		Information about the patient's condition
	FMs' information sources	Searching for information independently
		Information from close people
		Information from HCPs
	Challenges in accessing information	Unsatisfactory information sharing
		Restricted information sharing

2.5. Data analysis

Data regarding manifest content were analysed following the inductive content analysis process (Elo et al., 2014). First, the audio-recorded interviews were transcribed verbatim and read through by a researcher before selecting the unit of analysis. The unit of analysis in this study was a sentence or an expression describing the experiences of an FM in response to the research aim. After that, the sentences and expressions were simplified and coded by one researcher. The codes were then combined into groups of similar content to create sub-categories, and these were compared to generate categories (Table 2). The data analysis was conducted in a research group of four researchers. Finally, the categories were combined to create main categories (Elo and Kyngäs, 2008).

2.6. Ethical considerations

The study was approved by the Ethics Committee of the University of Turku (approval number 15/2019). Research permission was obtained from each hospital accordingly. All procedures were conducted following ethical standards regarding the participants' autonomy, privacy, and anonymity (World Medical Association, 2013). Written informed consent was obtained from all participants.

3. Results

A total of 19 FMs (11 women and eight men) of palliative care cancer patients participated in the study. A detailed description of the participants' characteristics is presented in Table 2.

3.1. Family members' experiences of psychosocial support

FMs' experiences of psychosocial support in palliative inpatient units involved the main categories of Support *FMs hoped for,* Support *practices in the care unit and Informational* support *for FMs*.

The categories and sub-categories are presented in Table 2.

3.2. Support family members hope for

The support FMs hoped for consisted of the categories *FMs' opportunities to have supportive interactions* and Support *aimed at FMs* (Table 2).

Table 2
Characteristics of the participants ($n = 19$).

	N (%)
Female	11 (57.9)
Male	8 (42.1)
Age	Mean 61.35 (range 41–80)
Family member relationship to the patient	
Spouse	10 (52.6)
Parent	3 (15.8)
Child	4 (21.1)
Ex-spouse	1 (5.3)
Friend	1 (5.3)
Patient diagnosis	
Colorectal cancer	4
Glioblastoma	3
Prostate cancer	3
Breast cancer	2
Gastric cancer	2
Liver cancer	2
Bladder cancer	1
Gynecological cancer	1
Other	1
Time from diagnosis	Mean 1.43 years (range 2 months–8 years)
Treatment time in current unit	Mean 2.3 weeks (range 1.5 weeks–6 months)

Regarding the category *FMs' opportunities to have supportive interactions,* FMs mentioned that, because they felt they were in a vulnerable situation, they would have wanted permanent care relationships with the HCPs to form a confidential relationship with them.

ID13: "I wish that we could know each other because this is a rather sensitive subject and place"

FMs brought up challenges in opening up about their concerns and matters they wanted to discuss, and they considered their issues too sensitive to share with persons who were unfamiliar to them.

ID5: "all the nurses here seem to be able to discuss, but they should be a little more familiar for that I could open up"

Additionally, as the HCPs were often changing, the FMs wished they could freely express their concerns without needing to repeatedly explain things to different carers.

ID17: "because [the nurses] are constantly changing, there is not just one with whom I could share matters and talk"

FMs wished that HCPs would have an empathic approach so it would be easier to communicate with them and approach them. Several FMs also underlined if HCPs would have shown more empathy the FMs would have felt more supported. Additionally, although the FMs felt that HCPs should be compassionate and warm, they conveyed that these aspects were not always realised in their encounters.

ID12: "that you would receive compassion and empathy and such… this should happen more"

ID4: "the nurses…are kind of active… really competent… but not the kind of warm-hearted people"

Some FMs expressed that they would like to have the possibility to meet peers in similar situations with whom they could talk about their experiences. According to the FMs, there were no possibilities like this organised in the hospitals.

ID13: "maybe, just what you need would be a peer to chat with"

ID8: "if there is anything that needs improvement, it is the peer support"

The category Support *aimed at FMs* included FMs' wishes to have some support explicitly focusing on them. FMs experienced that the current support was concentrated only on the patients, and there was not much support provided for the FMs, even if that was something they felt would be important to receive.

ID12: "yes, I think that family members would need to be paid attention to as well"

ID19: "not really, at least I haven't really seen [support for families]; I feel like it's more focused on supporting the patient than on supporting relatives"

Furthermore, in the hospital environment, FMs felt that to receive support, they needed to request it from the HCPs. However, they wished support would be provided automatically: FMs hoped HCPs would ask them how they felt or if they wanted to talk with someone without FMs bringing it up themselves.

ID14: "so that I would have been told a little in a way what [the support] is… when I myself am not good at asking questions and finding out; that someone would have told me"

ID12: "that they would come here to chat …. one might ask that how you are doing…it would be nice to be noticed"

3.3. Support practices in the care unit

The main category, Support *practices in the care unit,* included categories describing the resources FMs received during inpatient care, such as *FMs'* support *resources* and *Supportive care environment.*

In the category *FMs'* support *resources,* FMs described self-acquired support and support that the care unit's HCPs had organised for them. FMs expressed that friends and other family members were important for supporting them in difficult situations. Some of the friends and family members worked in the healthcare sector themselves, and FMs felt that helped the support person understand their situation.

ID15: "children and family have supported me"

ID4: "there are certain people I can talk to; I just talked to that one friend on the phone who is a nurse"

Additionally, FMs described that they had arranged self-acquired contacts with psychologists and therapists to talk to and share their feelings with.

ID2: "I meet a specialist myself in private health care, and then I also meet a therapist"

ID7: "that my wife has [arranged] meetings with a crisis service… someone like that has visited, and we have all had it then"

FMs received support arranged by the HCPs in and outside the care unit. Support in the care unit took the form of conversations with HCPs; FMs mentioned nurses particularly as support providers, as nurses were the HCPs that FMs encountered most regularly.

ID16: "speaking, discussing, discussing with the personnel"

ID19: "I have once discussed with a doctor and then on an almost daily basis with nurses"

FMs said they had also support organised outside the care unit by HCPs. That included conversations with a pastor, psychiatric nurse, or psychologist, as well as seeking help from a local crisis centre.

ID6: "the hospital chaplain has been supportive, although we are in no way religious or anything"

ID8: "they have [offered] a crisis centre number and psychiatric nurse and such"

The category *Supportive care environment* consisted of issues that the FMs experienced as vital while the patient was in the inpatient unit. From the FMs' perspective, competent and empathetic personnel meant that HCPs were suited to work in palliative care, and such traits as work competence, empathy, warmness, and kindness were repeatedly mentioned by FMs. In addition, FMs expressed that an HCP was competent when they provided decent care and were devoted to their work.

ID13: "what I might see [as important] here is that the care is good… everyone is a professional here, they know their job"

ID11: "the personnel are qualified, and they focus on their work"

When asked about support experiences, FMs frequently declared that the empathy shown by HCPs was meaningful to them.

ID14: "[the nurses] are very cordial"

ID16: "[the personnel are] really considerate, empathetic in every way"

ID4: "when I don't know everything about the care… I feel like [the personnel] are always here for me, you can always ask"

ID2: "[the personnel] are really wonderful… I get the feeling that they really are present and listen and want to understand"

FMs described different experiences about the quality of the care. According to their answers, satisfaction with patient care was essential to FMs. When FMs felt that patient care was good, they felt supported. When the FMs had confidence in the care, they felt the patient was safe

and could leave the patient for a while to relax.

ID16: "the feeling of safety is absolutely brilliant here, and I could not have imagined a month ago that… [patient's name] would be here to be taken care of for a while, and I can just be at peace, just as I have no symptoms of panicking at all"

ID5: "at this ward, the care is much better than at those others; here, the treatment works"

On the contrary, FMs said that if there was a lack of confidence in the care, it caused burden and stress for them.

ID2: "I feel that have to be here at night… got the feeling that I do not trust what [medication] he gets"

ID10: "that there is that one nurse… and [patient's name] called me in a panic: 'come get me out of here'"

The supportive care environment also supported FMs' opportunities to be present in the care unit. FMs valued the possibility of being there, and a welcoming atmosphere that enabled FMs' participation and presence in the hospital was a part of the supportive experience. As a result, FMs sensed that their presence was accepted and that their wishes were considered.

ID4: "they have been very welcoming"

ID6: "I think all wishes have been very well received"

Additionally, FMs stated that suitable facilities, such as a room in which they could stay and spend time with the patient in the care unit, were also needed to enable their presence and participation.

ID2: "that it is possible to stay overnights, that there are such facilities here and… [we] have our own room"

ID15: "we got a single room… so in the morning I went home, and in the evening I came here again for the night"

FMs felt that the opportunity to have unrestricted visiting time and the possibility of staying as much as they wanted were also essential because some FMs felt they could not stop worrying about the patient if they were at home.

ID12: "I wouldn't be able to be in my own home; I would just spend all my time thinking about how [patient's name] is doing"

ID9: "the everyday encounter [with the patient] is important, and the fact that I spend that time with my father (the patient)"

However, FMs also mentioned they had faced experiences of inadequate support when referring to experiences that FMs found burdening. As a realisation, FMs described a feeling of being ignored.

ID14: "but none of [the personnel] have come; yes, they have been introducing themselves to the patient, but none of them have been introduced to me and none have come to talk"

ID4: "I wasn't even looked in the eyes, not greeted [by the personnel] when I came into the room"

Some FMs felt they were not seen or noticed and that no support was provided.

ID2: "not at all" (when asked if they had received support from personnel)

ID19: "at least I haven't seen that [kind of support]; I feel it's more focused on supporting the patient than on supporting relatives"

In some cases, communication was described as unfriendly, and FMs felt they were not welcome in the care unit or were spoken to in an unpleasant tone.

ID2: "inappropriate towards me and a complete lack of situational awareness … it feels like they would prefer it if I weren't here"

ID9: "but still the feeling that 'why are you coming here to ask and are you a professional and do you understand what's there'… so uh I'm not a professional but yes, I still want to know"

3.4. Informational support for FMs

Family members' experiences of informational support contained the categories of *FMs' informational needs, Information contents, FMs' information sources,* and *Challenges in accessing information.*

FMs' informational needs comprised elements of hospital care that FMs felt lacked information. FMs expressed that they would have needed more information about palliative care practices, including cancer treatments, prognoses, planning, and possibilities for care.

ID8: "yes, some information regarding these cancer treatments [would have been desired]"

ID 12: "how everything works here and what kind of treatment this is… because this is a hospital… this is a little different"

FMs also wanted general information about the care unit, such as contact information and guidance in the practices, to know how they could participate in care and what in-hospital care generally involved.

ID3: "we didn't even know that this was a palliative care unit"

ID5: "it would be nice if there was a little brochure about this unit and then just about these flowers, for example, or if I could bring something personal"

Additionally, FMs desired guidance regarding caring for the patient at home, as some patients expected to go back home for a while.

ID7: "At home then, there are all these challenges, so what do you do if there are problems? Where can I get help?"

ID19: "If I see that the relative's condition is getting worse and I can't cope anymore, then what should I do?"

A few of the FMs also wished for some guidance regarding possibilities for financial support.

ID13: "and I'm still a little unsure about what financial support and other things can be applied for"

ID16: "Social Insurance Institution matters and such" (more information was needed)

One aspect of *FMs' informational needs* was that FMs wished that information would be automatically provided to them, rather than them having to ask for it.

ID12: "that I would have been told a little bit about what… how the treatment is going, because I am not good at asking and finding out about things…I wish that they would have automatically told me a little… or at least more"

ID13: "that would have been, in my opinion, really good… a regular appointment with a doctor or nurse"

FMs also desired that the information that HCPs provided be limited to only what they wanted to know. They felt they did not want too much information about the patient's condition because they knew that the patient was dying, and the palliative care situation was already burdensome.

ID4: "I may not want to know beforehand… I avoid that information"

ID16: "I haven't asked for any time limits …and it doesn't really interest me, or I'm interested, but I don't want to ask" (referring to a prognosis)

The category *Information contents* included topics about which FMs had received information from the HCPs. For example, FMs described

being provided information about patient care that referred to what had been happening in the patient's daily care practices, symptom management, and the functions of the care unit.

ID15: "this medical information, it has been reported that these pains or symptoms are being treated because nothing else can be done"

ID2: "practical things, visiting times, overnight stays"

FMs stated that patients' medications, their type and purpose, were essential information and important to the FMs. It was also the subject about which FMs felt that HCPs offered information most regularly.

ID2: "medication is the top thing I have been informed about"

ID12: "there is a need to give medicine, so they have explained that they are now giving this and what it is"

FMs had also received information about the patient's condition, including the patient's daily status.

ID9: "and, of course, how father seems to be doing…or how he is feeling, is he feeling well"

ID13: "if I ask how his day has gone, then I am told"

In addition, FMs said that information concerning disease progression and cancer treatments was given to them.

ID4: "we discussed it so that I too could ask what this cancer is, how it develops, how it appears"

ID12: "there has been a discussion about it being cancer, and that it has spread"

FMs' information sources included the resources used or people from whom the information—mainly about patient care, illness, and treatment—was obtained. Regardless of age, all participants reported that they had searched for information independently, mainly online.

ID16: "mainly, I get information from the internet"

ID3: "everything can be found on the internet today"

Some FMs said they had also read the patient's medical reports to get more information.

ID14: "from the medical reports which have been obtained here… that information is available in those medical reports"

FMs described receiving information from people other than HCPs, such as relatives and friends, some with healthcare education, and such support was considered vital for some FMs.

ID10: "we have a daughter who is a special nurse in the intensive care unit, so she knows these things"

ID5: "well, I actually get [information] through relatives"

ID5: "[a friend] has worked at the cancer department herself, and so I get a lot of realistic information from her"

ID6: "usually the information then passes through to all of us [friends]"

Naturally, information was obtained from the HCPs in the care unit. FMs described information obtained primarily during conversations with doctors and nurses. FMs described conversations with nurses as informal and daily, and nurses were thought of as close and easily encountered, whereas opportunities to speak with doctors required an appointment.

ID19: "for the most part, I think I have received very good information from the nurses"

ID6: "there are many nurses, so from them absolutely"

However, FMs considered doctors essential information providers, and FMs felt that being present at a doctor's appointment with the patient was a great way to get information.

ID19: "I have pretty much relied on the doctor's appointments; I could say that if I hadn't been with my mother at the doctor's office, no information would have been received"

ID7: "well, usually, in my opinion, [information] has been obtained reasonably well, mainly from those doctors"

A few FMs also mentioned that they had received guidance from other professionals, like physiotherapists or social workers.

ID6: "the physiotherapist is really wonderful and has been running here constantly and guided us"

ID1: "I have talked with the social worker earlier"

The category *Challenges in accessing information* described problems that FMs had experienced during the hospitalisation period. FMs had undergone unsatisfactory information sharing, referring to contradictory information about patient care and prognoses from the HCPs.

ID7: "of course, there are some contradictions with these prognoses"

ID14: "instructions were received, and then when we got home from here, other instructions were received, and there was a contradiction"

Furthermore, FMs described that "shocking" information about the patient's situation was sometimes given suddenly without preparation, causing anxiety for the FM.

ID6: "I received shocking information quite abruptly that [patient's name] at risk of dying… probably that was the situation, but then somehow it came the way that… that of course I panicked a little"

ID4: "it was a terrible thing (getting information in the middle of the night), and I couldn't sleep, we were both horrified, I had never heard of that kind of thing before and then [the nurse] blurted it out in such a way… that it came so wrong"

On several occasions, information sharing had also been restricted. Almost all FMs reported the need to be highly proactive in demanding information from HCPs; otherwise, FMs would get no information.

ID18: "there is no situation in which someone comes to ask you if you would like to know more about this; there has not been any, no question like this"

ID13: "yes, you get the information, but you always have to ask and call on your own initiative"

In addition, FMs felt their access to information was limited, and they did not always get answers to their questions or the chance to speak to someone. Sometimes, they believed that their need for information was questioned.

ID14: "very scarce… [information from personnel] is very scarce"

ID9: "how difficult it was to get that information on medication, for example"

FMs mentioned repeated problems in communication between families and HCPs repeatedly, and FMs felt that the HCPs often ignored them.

ID13: "[patient] care is good; there is nothing wrong with that, the only problem is the communication with relatives"

ID4: "if you try to ask, then the doctor turns their head and does not answer"

4. Discussion

This study aims to describe FMs' experiences of psychosocial support in specialist palliative care inpatient units from their perspectives. Three main categories were identified: Support FMs hoped for, Support practices in the care unit, and Informational support for FMs. FMs described their support experiences in relatively little detail. There were a few in-depth descriptions of what concrete support actions were implemented, what the conversations with HCPs were about, or at least what issues they covered. We know that FMs of palliative care patients often put their own needs aside while concentrating on the patient's needs (Wang et al., 2018), and that they often do not know about possible support options (Oechsle et al., 2019; Ullrich et al., 2017). This issue was possibly reflected in the FMs' descriptions of their psychosocial support experiences, and the FMs did not necessarily recognise all of their options of available support. Therefore, anyone encountering FMs in a hospital setting, including HCPs, should be aware that FMs do not always know the support opportunities they could access or even recognise their own needs for support.

The participants described their experiences of psychosocial support related to their coping, particularly, those related to their emotional and social elements in life. Overall, the participants did not describe physical, financial, or service-related support practices in their answers, although these have previously been identified as components of FMs' support (Wang et al., 2018). Additionally, spiritual matters were not discussed or brought up by the FMs. Some participants briefly mentioned meetings with a pastor, but pastoral care was perceived as more psychological and emotional support than spiritual. The minimal attention to the spiritual aspect is not surprising considering the Finnish cultural context, as religion generally does not have an active role in people's everyday lives in Finland. In addition, pastors are available in care units upon special request, but not frequently. Nevertheless, spiritual elements are always present in some way in dying care, regardless of whether the person is religious (Hui et al., 2021). Therefore, there should be more options for non-religious spiritual support, which could focus more on a person's general life philosophy and not only on some specific religious perspective that may feel distant to the FMs or patients.

As in earlier studies (Bainbridge et al., 2018; Donnelly et al., 2018; Robinson et al., 2014; Røen et al., 2018; Virdun et al., 2017), when the physical environment enabled presence and participation and had a welcoming atmosphere, FMs felt supported. Therefore, in hospital settings, attention should be paid to ensuring an appropriate care environment that allows FMs' presence and participation, and practices in care units should be constructed to limit their involvement as little as possible. In addition, in this study, HCPs' characteristics and the sense of safety and security concerning patient care were also valuable for the FMs, meaning that competent, suitable personnel and good patient care supported them. When a patient is hospitalised, FMs need to be able to trust that the HCPs will care for their loved ones in the best possible way, so the HCPs' professionalism, performance, and willingness to implement family-centred care are emphasised.

According to the results, the importance of information provision and the possibility of obtaining information in the hospital environment was essential to the FMs'. However, the FMs received information mainly because they actively demand it from the HCPs; the information exchange, in general, has been acknowledged to be an aspect with which FMs often are dissatisfied (Wang et al., 2018). While the patient is in hospital, the FMs depend entirely on the HCPs' provision of information about the patient's situation. Problems in communication and information sharing and difficulties in approaching the HCPs (Robinson et al., 2014) are burdening for FMs. Therefore, being appropriately informed about all aspects of care when the patient has a serious illness and is in worsening condition should be considered a core element of FMs' support in hospital settings. In addition, in this study, FMs' need for information was sometimes questioned: they were treated as outsiders and not given information by the HCPs. Insufficient information sharing and poor communication between HCPs and families were harmful elements that negatively affected the support experience. Therefore, more attention should be paid to HCPs' skills in interacting with families (Lee and Cha, 2017; Robinson et al., 2014; Ullrich et al., 2021). Moreover, alternative forms of communication, like written or electronic channels, should be considered, as not all FMs prefer or actively seek conversations with HCPs.

Concerning the FMs' psychosocial support, the HCPs mentioned physicians and nurses most often; other professions, like physiotherapists, social workers, and pastors, were mentioned only a few times. This may be because therapists and pastors are only included if there is a particular need for their services. For example, social workers in the Finnish healthcare system are mainly responsible for guidance and assistance with financial matters, social benefits, and arranging reasonable care at home (Saarto and Finne-Soveri, 2019). Additionally, social workers are not continuously available on hospital wards; rather, they work as a part of a multi-professional group. In contrast, nurses and physicians coordinate the overall care, organising and implementing daily support, and their role as support implementers should be acknowledged, for example, in designing support interventions in hospital care.

In the current study, care meetings and family conferences—where various professionals are present to arrange support and share information—were not available as a part of the support provided by the HCPs. However, FMs wished for support that was automatically provided and was aimed explicitly at the FMs. Additionally, information sharing was viewed as unsystematic, and FMs found they had to be highly proactive in demanding access to information. Systematic support and information-sharing procedures for FMs should be routine models in palliative care; as previously stated, FMs do not always recognise their support needs. Furthermore, not everyone feels comfortable approaching HCPs in unfamiliar environments and situations (Ullrich et al., 2017), and if it is necessary to demand support and information, some FMs will be left without it.

4.1. Strengths and limitations

This study includes participants in one country in a limited cultural and economic context, which affects the transferability of the results. However, the fact that the study was conducted in large hospital districts is a strength, as is the fact that the analysis aims to describe the lived experiences of the FMs and was conducted by several researchers. The study was performed in four specialist palliative care inpatient units, where HCPs have special expertise in palliative care, and comparisons with other settings must be made with caution. Purposive sampling was used to find informants who expressed their perspective and were involved in patient care, i.e., had experience in the hospital environment. Recruitment by nurses may have limited the selection of participants by excluding the most burdened FMs. There is also a risk for bias if those presumed to express positive experiences were favoured, even if the participants raised criticism concerning the support. The data gathering reached a point of saturation, which increases the credibility, as does having the data analysed by a research group. However, the saturation point is hard to define, as there is always a possibility for new insights, even when it does not seem probable. As this study aimed to describe the FMs' experiences rather than fully understand them or be theoretically constructive, the code saturation was pursued and reached (Hennink et al., 2017). The participants could not add comments, corrections, or feedback to the transcripts or the results. The COREQ 23 checklist (Tong et al., 2007) was used to ensure specific data analysis and reporting.

5. Conclusions

According to FMs' experiences, support focusing particularly on the FMs, safe quality patient care, proper access to information regarding

the patient's care and condition, and genuine encounters with HCPs were the aspects that seemed to be the most important to the FMs.A hospital inpatient setting is often an unfamiliar environment for FMs, and this can hinder them from requesting and receiving support and information. Therefore, the systematic provision of support and information should be a routine model in palliative care. Additionally, a care environment that promotes FMs' presence, participation, and family-centred care is essential in FMs' support and should be considered when developing family involvement in palliative care. Care environments should feel safe and welcoming to FMs, and HCPs should be aware of how their professional performance and attitudes affect the psychosocial support of FMs—should also be noticed in their palliative care training. Furthermore, the importance of FMs receiving sufficient information, and FMs' dependence on HCPs to share the needed information, should be acknowledged. Hence, more attention should be paid to successful information sharing between the HCPs and FMs in palliative hospital care.

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CRediT authorship contribution statement

Soikkeli-Jalonen Anu: Conceptualization, Methodology, Investigation, Data curation, Writing – review & editing, Writing – original draft, Visualization, Funding acquisition. **Mishina Kaisa:** Methodology, Investigation, Writing – review & editing, Supervision. **Virtanen Heli:** Investigation, Writing – review & editing. **Charalambous Andreas:** Writing – review & editing. **Haavisto Elina:** Conceptualization, Methodology, Investigation, Data curation, Writing – review & editing, Funding acquisition, Supervision, Project administration.

Declaration of competing interest

The authors have no conflicts of interest to declare that are relevant to the content of this article.

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