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Behind the scenes of palliative care: Qualitative study with oncology family caregivers

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ABSTRACT

Purpose: Long-term caregiving tasks can be exhausting for family caregivers, resulting in high psychological morbidity. The study aims to explore the experiences, challenges, and strengths of family caregivers providing care for cancer patients in palliative care, in-patient or at home.

Method: Nine caregivers were included, predominantly women aged 34 to 70, from various regions of Portugal. They participated in four focus groups between May 2021 and May 2022, held online due to COVID-19 restrictions. A qualitative research methodology was employed, using semi-structured interviews conducted through focus groups. Data were analyzed using thematic analysis to identify key themes in caregivers' experiences.

Results: The study revealed several challenges, categorized into three main themes, listed in order of frequency: (lack of) communication, pain and suffering, and caregiver burden. Death emerged as a meta-category. Despite these difficulties, caregivers identified sources of strength and support that helped them cope during this time.

Conclusions: The findings underscore the profound impact of caregiving on family members and highlight the need for enriched support systems and interventions to reduce caregiver burden and suffering, boosting their resources. Despite its limitations, the study's diverse and rich content illustrate the value of group settings in fostering belonging and comfort among caregivers.

1. Introduction

According to data from 2020, cancer accounts for nearly 10 million deaths globally (World Health Organization, 2022) and in Portugal it is the second cause of death (Direção Geral da Saúde, 2022), making cancer's impact on family narratives, therefore, even more pronounced. Most importantly, cancer is not just an individual diagnosis; it challenges our beliefs and confronts us with mortality. It causes grief over a lost identity, whether as a 'healthy person' or as a family untouched by cancer. Cancer brings uncertainty, threats of loss, and changes in family dynamics, often leading to guilt, resentment, and helplessness (Góngora, 2002; Rolland, 2018). Despite all these challenges, individuals and families persist in preserving hope. These mixed feelings obstruct the already winding path ahead.

As cancer progresses, it often becomes necessary to involve a partner, a son, daughter, or other relative in the tasks of daily caregiving. These individuals, often referred to as informal caregivers or, for the purpose of this paper, family caregivers, play a crucial role in providing essential care and support throughout the disease.

1.1. *Who are these family caregivers?*

Family caregivers tend to be women (Walsh, 2016). This became particularly and increasingly true in the wake of the Covid-19 pandemic, a period that intensified gender inequalities in the labor market and reinforced traditional gender roles (European Commission, 2022). As life expectancy continues to rise, family caregivers are often themselves living in their retirement years (Garland, 2019) and experiencing their own health issues (Jansen et al., 2021). In the past two and a half years and given the ramifications of the Covid-19 pandemic, people have expressed concerns about receiving help from the outside (Oliveira et al., 2022); in addition, resources provided by the government have been too scarce to attend to everyone's needs, which in turn increased caregivers' daily hours of care provided (Eurocarers/IRCCS-INRCA,

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2021). On top of this, it is important to highlight that family caregivers frequently undertake this role with almost no preparation and/or education to do so (Hashemi et al., 2018; Northouse et al., 2012). Although not all informal caregivers are recognized with the *status of informal caregiver*, in Portugal it can be granted if several specific legal criteria are met, such as being over eighteen, having the necessary health conditions, and being available to provide care (Decree-Law nº 1/2022, 2022). In addition to seeing their role recognized, the aim is to receive training to provide adequate care and to benefit from periods of rest, psychological support and several public policies aimed at informal caregivers (Decree-Law nº 1/2022, 2022).

1.2. *Caregiver burden: Can we prevent it?*

The long-term involvement in daily caregiving, which requires bathing, giving medication, providing emotional support, and many other everyday activities, can be exhausting for family caregivers (Areia et al., 2017; Hashemi et al., 2018). Those who care for individuals with advanced-stage cancer receiving palliative care appear to experience a substantial decrease in their quality of life (Koçak et al., 2022). Studies showed that caregivers are considered irreplaceable pieces of healthcare teams (Hashemi et al., 2018). Nonetheless, they are not provided with the necessary support (e.g., Oliveira et al., 2022b; Sercekus et al., 2014).

Palliative care, which aims to improve the quality of life of the whole family when facing the problems of a life-threatening illness as well as to prevent or alleviate the physical, psychosocial, or spiritual suffering of patients and family members (World Health Organization, 2020), could be a valuable resource given how it is able to buffer the impact of long-term chronic illnesses and, in particular, cancer. Although palliative care is required for an extensive range of life-threatening illnesses, 34% of the adult population in Portugal requiring palliative care has received a cancer diagnosis (Comissão Nacional de Cuidados Paliativos [National Palliative Care Commission], 2021). The literature on the topic indicates that palliative care, in the earlier stages of oncological disease, improves the family's quality of life and caregiver confidence (Cameron et al., 2004), helps prepare for death (Sarmento et al., 2017), and decreases the caregivers' burden and psychological distress (Sun et al., 2015). Hence, even though psychological morbidity is very prevalent amongst family caregivers (Areia et al., 2019), timely and effective interventions might be able to avert or at least diminish it.

1.3. *Current study*

The Covid-19 pandemic served to both reassess and increase attention on the role of those individuals who, often alone, care for patients with a chronic and disabling condition. Moreover, if human life expectancy is increasing along with cancer diagnoses, it thus becomes imperative for mental health professionals to focus on enhancing the quality of life and ensure the comfort of the entire family during times of crisis. The present paper is part of a larger study which intends to focus on the experience of family caregivers of cancer patients and how they are cared for in palliative care settings. To accomplish this, caregivers' experience of caring for a terminally ill cancer patient was examined, identifying their main obstacles at this stage, but also their strengths and resources throughout these difficult times. The latter allowed the research team to gain insight into their needs, what skills or resources they already had at their disposal to overcome the said obstacles, and what was lacking. Here we focused on families with a person with cancer receiving palliative care treatments, in-patient or at home.

2. Methodology

The study followed a qualitative research methodology. The former was to better understand the experience, challenges, and strengths of families in palliative care settings. The researchers aimed at filling in the blanks on how family caregivers of cancer patients perceived their own experience during their loved one's illness. To ensure rigor and organization, for the purposes of this paper, they followed the Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014).

To fulfill these aims 4 focus groups were conducted with the referred family caregivers. They followed a semi-structured interview with "a group of people who have experienced the same problem" (Rubin and Rubin, 1995, p. 139, *cit in* Wilkinson, 1998). These occurred online through *Zoom* conferencing due to restrictions arising from the Covid-19 pandemic. Even though the final interviews did not take place during any surge in infections and occurred after a considerable percentage of the population had received booster shots, the online method was kept for reasons of consistency and because it was seen as an opportunity to gather people from different cities in the same meeting during a convenient time of the day for all of them.

2.1. *Participants and recruitment*

For the purposes of this phase of the project we reached out to several palliative care institutions and some organizations. In each, a person was defined as "the contact person" who managed the invitations made to the family members to participate in these focus groups. A flyer was sent to these health teams/organizations to simplify the caregiver recruitment process. When family caregivers showed interest and gave consent, their contact information was provided to the first author, who then communicated with the participants, usually by telephone, explaining the necessary conditions to participate (i.e., having access to a computer, tablet or phone with internet), the nature of their participation in this study, and its purposes. If they met the criteria and were willing to be part of the study, their availability during weekdays or Saturdays was registered to assign groups and schedule times.

As described in Table 1, participants were drawn from several palliative care services or institutions and across a large geographical area of the country. The inclusion criteria included age, the person's role, and capacity to participate in the groups: all subjects were older

Table 1
Sociodemographic characteristics of family caregivers and focus groups conducted.

Sex	
Male	2 (22.2%)
Female	7 (77.8%)
Age	
30–39	3 (33.3 %)
40–49	2 (22.2 %)
50–59	1 (11.1 %)
60–69	2 (22.2 %)
70–79	1 (11.1 %)
Relationship to the patient	
Cousin	2
Mother	1
Nephew	2
Son/daughter	2
Spouse/long-term relationship	2
Primary informal caregiver	
Yes	6
No (secondary)	2
Unspecified[a]	1
Employment status	
Full-time job	5
Retired	2
Unspecified	1
Unemployed	1
Composition of focus groups	
FG 1	2 female participants (46 and 53 years old)
FG 2	2 female (65 and 66 years old) and 1 male (67 years old) participant
FG 3	2 female participants (34 and 35 years old)
FG 4	1 female (40 years-old) and 1 male (37 years-old) participants

[a] There is no clear information about the topic.

than 18 years-old, family caregiver (primary or secondary) of a person with cancer receiving palliative care, and he/she had to be able to enter the *Zoom* meeting (or could have the help of someone like a family member to enter the meeting) – platform chosen for the said groups. In the 4 focus groups, there was a total of 9 participants. Around 78% were female and the age of caregivers ranged from 34 to 70 years old (M = 49.67; SD = 14.53). Table 1 describes the composition of the focus groups, some of participants' demographic characteristics, their role in the family, relationship with the patient and their work status.

Additionally, it is important to highlight that we are including only caregivers of people receiving palliative care.

Our focus groups are small in size which, in the family caregivers' situation, we believe was an advantage that made them feel more secure and comfortable sharing experiences. In fact, three out of four focus groups included only two family caregivers precisely for the above-mentioned reason. Nevertheless, the interviews took place considering the time schedule for that activity by those who were present.

2.2. Data collection

The interview script was first tested with one group of family caregivers to access its feasibility and quality of the collected data. One question was added based on these pilot interviews: "What are the main resources that you have identified in yourselves over this time as caregivers?". In the last focus group one multiple choice question about the most relevant obstacles for caregivers, considering their experiences, was added. That was based on the ongoing preliminary thematic analysis of the previous groups and to prepare the following step of the research project. The interview guide included 1) palliative care institution/setting protocols for welcoming the families, 2) perceived loopholes for fulfilling the family needs, 3) communication between the family and health professionals, 4) main obstacles for the family caregivers and their strengths, 5) formats for prospective interventions.

The focus groups took place between May 2021 and May 2022. A few days prior to the defined date for each group, participants received an email with all the instructions to enter the Zoom meeting, as well as the informed consent, in which they gave permission to record audio and video of the focus groups. The meetings lasted on average 78.50 min (between approximately 47 min and 112 min) and were conducted by the first author of this paper.

Data collection ended as soon as theoretical saturation was reached.

2.3. Data analysis

Each interview was transcribed verbatim to proceed to the thematic analysis (Braun and Clarke, 2006) of the participants' understandings, using the QSR NVivo 12 software. After reading the data and noting some first thoughts (Braun and Clarke, 2006) we adopted an inductive thematic analysis, following the steps proposed by (Braun and Clarke, 2006).

Patterns within the data were identified and units were organized into categories (Braun and Clarke, 2006) by the first author. These categories were then organized into overarching categories, based on similarities, creating the acknowledged central themes. Afterwards, the first author, the person most familiar with the data, selected the focus groups and its segments of data that included more relevant information (Campbell et al., 2013). Then, a second coder double coded this selected content to ensure consistency between categories (O'Connor and Joffe, 2020) and to improve the definition of each category. The main goal of this step was not to reach "objectivity" but rather to create a dialogue and discussion between researchers and, consequently, to have a more reliable category analysis (O'Connor and Joffe, 2020).

2.4. Transparency and openness

This study was authorized by the ethics committee of two institutions. Materials and analysis code for this study are not available to ensure participants' confidentiality. This study was not preregistered.

3. Results and discussion

Our findings offer a thorough understanding of the challenges encountered by family caregivers providing care for cancer patients undergoing palliative care and the resources identified throughout this path. The life of primary caregivers usually revolves around caregiving, particularly as the illness progresses (Oh et al., 2021). Thus, their priorities tend to take a back seat, and caregivers begin to spend less time with their hobbies and limit contacts with friends and family (Bevans and Sternberg, 2012). There were major challenges when finding people to participate in these groups during the first period, in 2021, mostly due to Covid-19 contingencies affecting both institutions and families. Once established, these focus groups allowed for rich and open-hearted discussions about these painful experiences as well as the resources and strengths caregivers identify and that they consider having built throughout the process, with themes ranging from helplessness, suffering, and burden to the conspiracy of silence, increased family conflicts and communication of the bad news.

One of the main research questions that guided our focus groups was "*Which are the main obstacles felt and experienced by family caregivers of cancer patients receiving palliative care?*" Even though we made a point of paying attention to the strengths and resources of family caregivers, the full interviews were analyzed to gather a more in-depth understanding of caregivers' experience and perception of obstacles. The thematic analysis of caregivers' focus group produced three main overarching categories on the obstacles: 1) communication, verbal and non-verbal, both with professionals and within the family system [*(lack of) communication*]; 2) the suffering related with the experience of witnessing their loved one hurt [*pain and suffering*]; and 3) the burden felt by caregivers [*caregiver burden*]. One additional theme – death – was identified as a meta-category present across all focus groups during the terminal phase of the illness. At last, positive aspects of being a caregiver – "caregivers' strengths" – were coded. All themes and subthemes are presented in Fig. 1. Table 2 describes the categories identified relative to the obstacles together with some participants' quotes in italics. To avoid any concerns regarding confidentiality, the names of the participants have been removed. Instead, their names were replaced by, for example, "FCG 1, II" – i.e., family caregiver number one, from the second focus group. In this way, each caregiver is identified by number within their focus group (e.g., 1, 2, 3), which itself also receives an identification number (e.g., I, II).

3.1. Caregivers' obstacles

3.1.1. The suffering and pain of caregivers (A))

The qualitative analysis of the focus groups revealed a central theme: the profound spectrum of the caregivers' suffering. This category expresses the experience of pain and suffering felt by both the caregivers and the patients, ultimately resulting in more pain felt by the caregivers themselves. Caregivers expressed a profound sense of empathy for the patients' physical discomfort, emotional anguish, and deteriorating health. Witnessing family members as "prisoners of their own bodies", as one of the participants observed, evoked a range of emotions, from sorrow and empathy to a deep-seated helplessness in the face of their inability to alleviate the patients' suffering entirely. These feelings of helplessness and fear could be more easily overcome with educational interventions to provide family caregivers with knowledge about symptom management (Luth et al., 2021).

Hence, this main category is clustered in two categories: A.1) seeing the patient suffer – the one with more references – and A.2) the caregiver's suffering. Category A.1 mainly coded citations that were somehow linked to the patient (e.g., "*Well, it's hard (…) to watch my daughter suffer, isn't it?",* FCG 1, II), and the helplessness felt when patients were

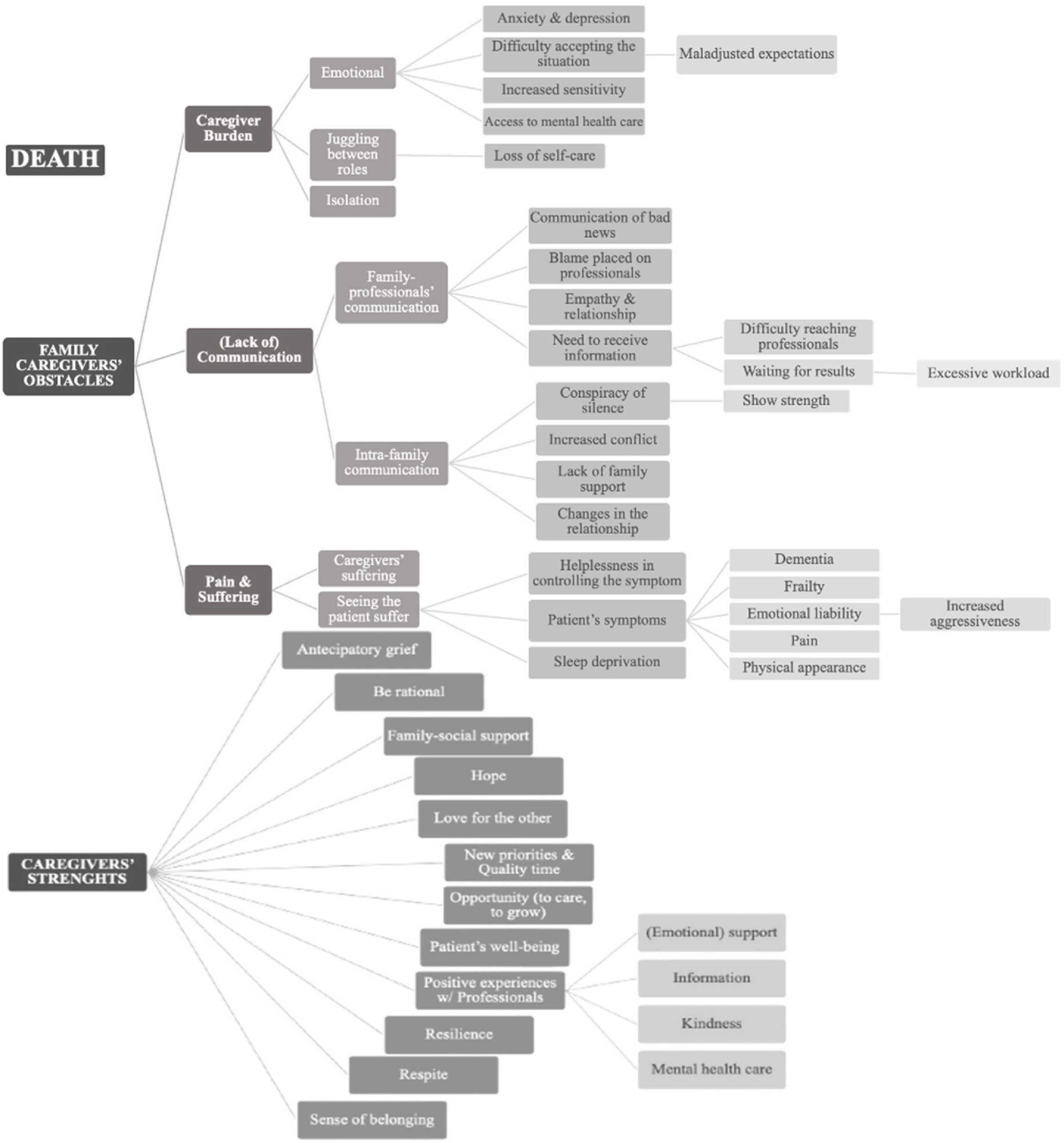

Fig. 1. Themes and Subthemes related to Caregivers' Obstacles and Strengths.

in pain, especially at home (e.g., "*That's what's hard for me, for now, that's what's hardest: not being able to do anything else …. I can't!*", FCG 3, II). On the other hand, A.2 dealt more with the general experience of suffering, not only related with seeing the loved one in pain but also about grieving (e.g., the loss, one's identity), anticipatory loss, and anguish. In line with previous research, we understand that the pain of the person with cancer can lead to severe suffering on the part of the caregiver (Ferrell and Borneman, 1999), contributing to their burden, which is intertwined.

A male caregiver shared that the most complicated time for him was when his mother was bedridden. He was a 67-year-old male, retired, who cared for his mother who had died a few months prior the focus group session. He shared that she "*became a prisoner of her own body … (…) until she reached a point where she couldn't speak, (…) … and she was losing the ability to see and hear.*". He said that it was hard for him:

> *I spent 20 hours a day with my mother. And there were really difficult periods (…) But it was also that, in a way, that allowed me, after those 2 or 3 months of watching my mother wither away in the end (…) that allowed me to mourn, (…). When my mother [finally] passed away I had practically done all my crying or almost everything, right?* (smiles). (FCG 2, II)

However, after listening to the other caregivers' experiences he felt that despite this painful period he experienced fewer struggles than others in the group because during most of his mother's illness she suffered little pain.

Relative to caregiver suffering (b)), we present the story of a 70-year-old female, caring for her husband with bowel cancer who shared her experience which revealed the pain she was feeling:

> *When I look at my husband and I see him really struggling, my imagination kicks in. And I said to the doctor "Oh doctor, I think I'm ready" and she said "No, you're not". Because I'm a very cheerful person. Or I was! I already said, the person I was 2 years ago died (…) I say "was" because I*

Table 2

In-Depth Description of Each Category and Subcategory regarding Caregiver Obstacles.

Categories and Subcategories	Description	Total Count for Each Category	Examples
A. PAIN & SUFFERING	Direct and indirect pain that caregivers feel throughout this period, navigating the obscure landscape of grief, psychological strain and helplessness as they provide care to cancer patients.	96	—
A.1. Seeing the patient suffer (SPS)	The struggles caregivers had seeing their loved one in pain, physically and emotionally.	66 total 20 SPS	“*Because it’s different to see a problem, for example, eating more of this or more of that, then replacing it or finding other solutions, than it is to see a person suffering*”, FCG 2, II
A.1.1. Helplessness in controlling the symptoms	The pain caregivers feel from being unable to help, to reduce their relative’s pain, which creates a feeling of helplessness and more suffering.	10	*“That’s what I’m struggling with for now, and that’s what I’m struggling with the most: not being able to do more (…) and that hurts*”, FCG 3, II *“And not being able to … be helpful! Not being able to do anything! Because … Sometimes she doesn’t accept it!*”, FCG 1, II
A.1.2. Patient’s symptoms	Even though this was not directly about the patient, their symptoms and its exacerbation also appeared to impact the caregiver’s experience. The following are some of the referred symptoms.	33	—
a. Dementia	—	3	“*He fell out of bed several times because he wanted to leave. It was 3am and he was calling me: "Why aren’t you here? Why do the others come in and you don’t?*”, FCG 3, II
b. Emotional liability (EL)	—	15 total 2 EL	“*You can sense it* [the sensitivity] *there: ‘Because you don’t have patience! Because you’re not calm! Because you don’t even have a profile*!’. No, it’s not … I also have feelings and I’m a person too”, FCG 2, III
b.1 Increased aggressiveness	—	13	*“He had been nervous and irritable, and the truth is that after the sessions he’s had* [with a psychologist], *he’s calmer”*, FCG 2, IV *“I’m not saying it gets rough, but it gets … Aggressive, with an aggressive way of speaking”,* FCG 3, II
c. Frailty	—	4	“*Of course, she’s super weak and frail and that’s that*”, FCG 2, IV
d. Pain	—	9	“*And he’s writhing around in pain and he says that the pain feels like someone’s clenching their feet, it’s a horrible pain*”, FCG 3, II
e. Physical aspect	—	2	*“So when we were talking to him or he was trying to talk to us, he couldn’t express himself and we had that image of the uncle when he was fine and now it’s getting worse, … the physical image … That counts too!”,* FCG 1, III
A.1.3. Sleep deprivation		3	“*I go to bed and I can’t sleep, because … We’ve even changed the mattress to one that he can jump on and I’ll stay right in my corner [laughs]! I can feel it! I don’t sleep! Because he gets up several times a night*”, FCG 3, II
A.2. Caregiver’s suffering	The ‘general’ experience of suffering, not related to anything specific but to the entirety of the cancer diagnosis and the progression of the illness, felt as the family caregiver.	31	*“But anxiety, anguish, thinking about death, thinking about what the aftermath will be like, living afterwards without my mother, is something that unfortunately torments me more often than it should, or that I would like.*”, FCG 1, IV
B. (LACK OF) COMMUNICATION	The challenges caregivers face in effectively expressing their needs – towards other family members and health professionals – understanding medical information, and fostering meaningful connections with healthcare providers, as well as changes in the relationships within the family, with the patient or other relatives.	94	—
B.1 Family-professionals communication	The dynamics of information exchange, its challenges, namely regarding the quality and amount of exchanged information, and the nuances of this complex relationships	57	—
B.1.1. Communication of bad news	How important information about the illness was disclosed and its impact for caregivers.	10	“*So she was surprised and upset that she hadn’t been given the news and that it had been given to her son - who she considers to be the most fragile person,* [laughs]”, FCG 1, IV
B.1.2. Blame placed on professionals	It includes apparent placing guilt on professionals, namely in relation to the way diagnostic processes were conducted.	9	“*There was that incident of leaving the … which they did, didn’t they?”,* FCG 1, II *“But it took from March to December before she actually started receiving treatment”,* FCG 1, IV
B.1.3. Empathy & Relationship	Subcategory about relationships and impressions of health professionals and their impact on the narratives of their experience.	11	*“No! I don’t think that’s a dignified way of treating people. I think the dignified way is to help people as people who are suffering, to help them in their suffering, but to respect them in their … As people capable of dealing with the situation”,* FCG 2, II “*The oncologist who was with her was actually a very … cold person. We even used to joke when we left the appointment, "Dr. [doctor’s name] was nice" - how unusual!”,* FCG 1, IV
B.1.4. Need to receive information (NI)	A subcategory that reflects the need caregivers have to receive illness-related information. Here we have included the obstacles inhibiting the reception of this information, both practical and more subjective.	27 11 NI	*“(…) answering questions. Because, especially when my mother was bedridden, there were … frequent doubts!”,* FCG 2, II *“On the other hand, the lack of information leads to anxiety. An informed person has more knowledge, more tools to protect themselves, to defend themselves and to deal with the situation!”,* FCG 2, IV

(*continued on next page*)

Table 2 (*continued*)

Categories and Subcategories	Description	Total Count for Each Category	Examples
a. Difficulty reaching professionals	The sense that communication channels meant to contact professionals are restricted.	4	*"And when I do manage to speak to the doctor - which isn't easy, there's a barrier in the administrative services so that the calls don't get through to the doctors",* FCG 1, IV
b. The stress of waiting (SW)	The anguish caused by the time gap between the physical examinations and being informed of their results.	12 7 SW	*"Or having no answers, or every time there's a CT scan and there's no result at the next appointment, the scan isn't ready yet. They say they'll call and a week goes by, two weeks go by and the doctor has forgotten to call",* FCG 1, IV
b.1. Excessive workload	This small subcategory represents one of the reasons (i.e., health professionals' workload) identified by the caregivers for the delay in informing the patients of medical exam results.	5	*"But it's not a criticism in the sense of sloppiness on their part! I think they are, in fact, overloaded with work!",* FCG 1, IV
B.2. Intra-family (communication)	It explores how family members, in particular family caregivers, navigate discussions related to caregiving responsibilities, express emotions, and cope with disagreements and with changes that occurred since the onset of the illness.	37	—
B.2.1. Conspiracy of silence (CS)	This subcategory identified unspoken agreements within the family and/or with health professionals regarding the non-disclosure of the patient's condition, important information, or emotions.	17 total 11 CS	*"But what we try to convey to him is … He thinks he's there to get better, he's not fully aware of the state he's in, and we try to convey that to him. "Look, you're fine!", "You're looking good!", "You're even getting fatter!" We try to show him that there is some hope, even though we believe and we are certain that there is no hope at all!",* FCG 2, I
a. Show strength	It was included in the conspiracy of silence sub-category because it was interpreted as, somehow, a way of withholding the expression of emotions which impacts caregivers' and patients' experience of this period.	6	*"And I can't let her see this!",* FCG 1, IV *"And I was completely winter inside, and I had to show him spring or summer in terms of emotions! I had the hardest time there*", FCG 1, I
B.2.2. Increased conflict	The heightened conflict within families, including with the patient, associated with the present situation.	9	*"And a lot of the times the frustrations are, in quotes, taken out on me, not in an aggressive way, but with a change that I notice I can't always tolerate! And when sometimes I'm already 'out of my orbit', I also know … That I lose my … (laughs) my wisdom and I also know that sometimes I don't react in the best way.*", FCG 2, III
B.2.3. Lack of family support	Feelings of loneliness and isolation in caregiving.	4	*"He came from a very dysfunctional family, with a lot of poverty … His mother died in January, his diagnosis was in February.. … (…). He has two other brothers who are married and have their families, but, unfortunately, they don't care about him*", FCG 2, I
B.2.4. Changes in the relationship	Depictions of before and after the illness in the caregiver's relationship with the patient.	7	*"(…) basically our greatest challenge at times is this …. It's this new … It's this new type of communication between us and sometimes between him and my father-in-law, between him and his sister, … There you go*", FCG 2, III
C. CAREGIVER BURDEN (CB)	It could be defined as the level of multidimensional strain perceived by the caregiver from caring for a family member and/or loved one over time (Liu et al., 2020). As an overarching category for this paper, it also includes what the authors interpreted as potential background and consequences.	84 total 20 CB	—
C.1. Emotional	This subcategory highlights some of the emotional challenges that might add up to the existing challenges of this period or be created by the latter.	44	—
C.1.1. Anxiety & Depression	Shares of a more depressed and/or anxious mood or moments with this connotation.	10	*"(…) It was easy to solve, changing habits or friends, it was easy to solve. But that was the first feeling of depression I had, which was when the adrenaline of looking after her wore off and she returned to a minimally normal life, I fell into a hole*", FCG 1, IV *"And I immediately get nervous and as I can't get to the phone straight away because I'm working, I end up feeling anxious",* FCG 2, I
C.1.2. Difficulty accepting the situation (DAS)	Difficulty in accepting the situation of illness and/or suffering, directly or indirectly.	17 total 15 DAS	*" 'Oh Doctor, for how long?'. And she won't tell me for how long. And here I am [nodding and expression indicating insistence] … I wanted to hear 'No! In half a year this will be cured!'. But it won't …*", FCG 3, II
a. Maladjusted expectations	Expectations about the course of the illness, which are not in line with reality and oftentimes may be due to the struggle in accepting it.	2	*"Exactly, because he went there, because when he entered the facility … (…) the hope was that he would get better! He went there to get better!*", FCG 1, I
C.1.3. Increased sensitivity	References that represent the perception of caregivers who are more sensitive to certain situations, such as crying more easily than in the past.	6	*"Now at the drop of a hat [imitates the sound of crying]. (…) I don't know, I've been tearful (laughs). I'm much more sensitive!*", FCG 1, III
C.1.4. Access to mental health care	Little access and importance given to mental health services, from the caregivers' point of view.	11	*"And that meant that perhaps [name of hospital] never offered us any kind of psychological support. (…) And I was the one who had to go looking for it (…)*", FCG 1, IV
C.2 Isolation	Isolation from the rest of the family and/or friends and acquaintances.	2	*"My social life died from that moment on! It wasn't that great, but it died right there! Because I had to keep people away, I had to block any chance of possible infection*", FCG 1, IV
C.3. Juggling between roles (JBR)	The struggle of balancing multiple tasks and life roles and/or when the caregiver must provide care for more than one person.	18 total 12 JBR	*"Yes, I have a 4-year-old girl who also needs to be looked after, right, and I don't have much time left because I'm working, right?*", FCG 1, III *"I'm caring for my parents, both of them in fact. (…)Although they are still independent, I can actually leave the house to work, but there's a level of dependence with many other things*", FCG 1, IV

(*continued on next page*)

Table 2 (*continued*)

Categories and Subcategories	Description	Total Count for Each Category	Examples
C.3.1. Loss of self-care	Caregiver's perception of a lack of moments for self-care, namely in terms of health, moments alone, among others, sometimes due to the need to juggle between different caregiving and life roles.	6	*"Because, unfortunately, my health … I'm not unwell, but I could be better"*, FCG 3, II

> *really think that the old me is dead. (…) But now (…) I've trapped myself in this illness.*
>
> *(…) As a wife, I also have moments when I might even give a rude answer! Because I'm exhausted! I even take the car keys and go for a drive! (…)*
>
> *That's why I even went to the very bottom and asked for help. I went to the psychologist, and I said "I need help. I'm asking for help!" And I even went so far as to go to the family doctor and ask for something to take, to calm down. And these psychologist appointments help a lot!* (FCG 3; II)

3.2. *The (lack of) adequate communication (B))*

Another central category that resonated was the intricate web of (mis)communication. This main category is not only about what people say, but also about what they hear, their relationship dynamics, and the way they deal with all of the above. This is a period when tensions may increase, family roles may change, and when it is necessary to deal with how communication and information from professionals is delivered (or not) to families. This category is about the anxiety created by the lack of information, as one of the caregivers mentioned. Caregivers expressed that the barriers to access health professionals, especially doctors, as well as the "void of answers" (FCG 1; IV) associated with how the wait for exam results generates a considerable emotional strain. As one caregiver mentioned "*the lack of information makes people anxious*". They pointed to several important ways where they might feel more 'in the loop', involving both patients and caregivers in multidisciplinary conferences and in the decision-making process being a positive step forward (Sklenarova et al., 2015). Another significant barrier was the delivery of disheartening news – the tone, the context, but also the content of this bad news shared with patients and families.

> *In one of the visits, the doctor and nurse were talking about my mother's death in front of her. Which is something that may even be accepted, but it should have happened only after asking if it was acceptable or not. So, there was a lack of respect for the patient and the family* (FCG 2; II)

The 'conspiracy of silence' phenomenon was one of the subcategories most identified in this overlapping category (cf. Table 2, B2.1.). It is symptomatic of communication issues and is generally characterized by family members/health care teams withholding full or partial information from the patient, which might occur due to scarce information, fear of losing the loved one, lack of education in communication skills, stress, burden (Lemus-Riscanevo et al., 2019), or others. There is the perception that the patient *knows* but communication barriers hinder an honest dialogue on the matter (Ibañez-Masero et al., 2019), as one participant reported: "*Now, even today, I don't know if …, I think he's not stupid and that he must know*" (FCG 3; II). While there is a determination to protect the patient's emotions, the obstruction of communication channels intensifies the sense of loneliness, playing a role in the process of unresolved grief at the same time (Ibañez-Masero et al., 2019). However, the opposite may also occur: patients who want to protect their caregivers, especially if the patient is a parent and the caregiver is their son/daughter. In this case, the patient (i.e., the parent) feels that he/she "should" be the one taking care of the other. The latter was shared by one female caregiver who sensed that her parents were "afraid" of what she might hear and attempted to protect her feelings: "*Or because they were afraid of what I might hear* (…) *Or to protect me,* (…) *they told me 'You'll have plenty of opportunities to participate* (…)*' (…) I don't know if it was meant to protect me.*" (FCG 2; IV). Our findings show both omissions of information from the patient, as well as an apparent compromised communication between patients and family caregivers about illness-related aspects. Here are two different examples:

> *I called her [*the medical doctor*] beforehand, spoke to her and said "Doctor, I can't say this in front of him!", telling her what I had to say. During the appointment we spoke in a language in which only she and I would understand exactly what we were talking about. She prescribed what she thought she should prescribe for his cognitive issue. She told him it was just a few vitamins (…). So, in other words, sometimes you can spare the patient things that he probably doesn't want to know! Or he won't be able to deal with …* (FCG 2; IV)
>
> *And I know that one day he will [*die*]. Now I haven't talked to him about it yet. I don't want to talk to him [*about it*]* (FCG 3; II)

The conspiracy of silence is also about intra-family communications and relationship issues. Oftentimes, conversations are marked by what is unsaid or unspoken, where emotion often hindered open discussions about the patient's condition and end-of-life preferences. There is also the escalade of conflicts within the family system dealing with a common enemy – the cancer. A 35-year-old female caregiver caring for her husband with a brain tumor talks about her struggles dealing with the relationship changes they were experiencing:

> *My husband and I have been together since we were kids! For almost 20 years! We have a past. And today we have a different present! So, I know [husband's name] …. From 19 years ago! And today I know another [husband's name]. And that change in me … It was a bit devastating, because I noticed changes in him, (…) when we got to radiotherapy, I started to feel some … small differences. But in May, when he started chemotherapy …. Then yes! I felt - and sometimes still feel - aggressiveness, anger, frustration, … ! (…)*
>
> *These changes have been very devastating for me, because I had a husband, a boyfriend, a FRIEND! And suddenly … That intimacy was gradually changing. (…)*
>
> *Accepting this new situation, one being imposed on both of us, but on the rest of the family as well, because they also feel this change.* (FCG 2; III)

For some participants, such as the one in the previous dialogue, one of the main challenges was facing the "afterwards" of the relationship with their loved one. Hierarchies of power changed as the illness progressed. In line with Areia et al. (2019), the grieving process is also about dreams, social and joint plans, and so on. Therefore, in line with the existing literature, targeted interventions to enhance communication efficacy for caregivers in the palliative care context are of significance.

3.3. *Caregiver exhaustion (C))*

According to the literature (e.g., Bevans and Sternberg, 2012), our participants reported considerable amounts of exhaustion. Zarit et al. (1986) defined burden as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative" (p. 261). Therefore, this section delves into the multifaceted dimensions of caregiver exhaustion, encompassing what we considered as factors and domains that contributed to it. All caregivers reported experiencing a sense of burden to some extent, with the emotional state appearing to bear the greater toll, often linked to mental health issues.

> *The first feeling of depression I had was when the adrenaline of caring for her wore off and she returned to a minimally normal life. I fell into a hole.* (FCG 1; IV)

Some caregivers stated that they “had to ask for help” at some point; otherwise, they would not have been able to continue to manage their role as caregiver.

> *Now, it’s like Mr. Caregiver 2 says, we come to a moment when we must ask for help, and I did that. And I’m glad I did! I asked for help because I couldn’t take it anymore* …. (FCG 3; II)

We interpreted that the latter could be linked with the fact that they may be living for the disease and/or juggling between the role of caregiver and other roles, such as the role of mother, sister, employee, friend, or others. Balancing the responsibilities of caregiving with other existing roles introduces a dynamic that requires continuous adaptation. The illness itself, the need for continuous adjustments and the changes in daily life and family dynamic (Rolland, 2005) together with very few periods of rest fuel this growing fatigue. For example, a 37-year-old male caregiver in our focus group was caring for his mother – and for his father, with a different illness – and was also actively invested in his professional life. He reported feeling that, due to the demands of being a caregiver, his attention “*eventually tapered off - sometimes exaggeratedly so – (…) exclusively on protecting the two of them [*the parents*]*” (FCG 1; IV), recognizing a reversal of roles between the parental and filial subsystems.

> *And there is a protection that was perhaps excessive at times. Today I can look back and it probably shouldn’t have been! I could have breathed more! And that brought a lot of exhaustion and some emotional imbalance on my part. That was when I asked for help (…).*
>
> *I feel I have neglected myself over these 4 years, even my health, …. everything! Because the focus was always on them! On top of that, with a pandemic (…) Where that fear, those paranoid things we talked about at the beginning, in this case with a cancer patient in the house, was something …. There’s no way this can come into the house, right! My social life died from then on! It was not great anymore, but it died from then on!* (FCG 1; IV)

Our focus group discussions showed that caregivers frequently feel they are “less worthy” of care or hesitant to mention their own problems (Hudson et al., 2004), as they consider themselves not the ones with the physical illness. Nonetheless, some referrals to palliative care were due to caregiver exhaustion. The difficult access to mental health care services was seen as an obstacle: caregivers appeared to feel the need to have easier and greater access to these services, for themselves and their family members. The latter is in line with previous studies (e.g., Sklenarova et al., 2015) in which this absence of or the difficulty in accessing mental health services contributes to the caregivers’ exhaustion or, at least, shows that sufficient measures to prevent it are not being put in place.

Finally, there was the difficulty in making peace with the current situation. According with Rodenbach and colleagues (2019), caregivers occasionally feel overwhelmed with the awareness that their relative or loved one is indeed dying, sometimes finding themselves surprised by the “premature” death of the patients. Even the ambivalence between the "rational" and the "emotional" sides often seems to be present, as one of our participants described: “*The rational part of me knew that it was a very short journey. But my emotional part was always hoping that it would work out! Anything could happen! It could get better, right? Because he was young, 56 years old!*” (FCG 1; I). This process of acceptance introduces an additional layer of emotional complexity, further exacerbating the burden they carry.

> *I have always had, since I first became aware of death, a great difficulty in dealing with death itself and with the death of those who are close to me* (FCG 2; IV)

3.4. Embracing the presence of death

3.4.1. Death is part of life

- Says one male caregiver who cared for his mother.

Death was present across all focus group conversations in which family caregivers described their experience. A cancer diagnosis reverberates throughout the entire family, in particular, during the terminal phase of the illness, where death ‘dominates’ the family (Rolland, 2005). Despite being *an opportunity* – to care, to say goodbye, to create memories, and so on – death-related issues are explicitly or implicitly present. Participants expressed a range of emotions as they confronted the reality of an impending loss. Sometimes, when talking about death-related issues, such as anticipation of death or bereavement, caregivers showed how this impacts other domains, even contributing to the suffering they feel:

> *But sometimes I even ask the psychologist "Is it possible that it’s normal for me to be like this?" I face it, I face it. And I know that one day he will (die). Now I still haven’t talked to him about it. I don’t want to talk to him. Because I know that he will (die) [gets emotional]* (FCG 3; II)

Or, on the other hand, they perceive death as an inherent part of life’s journey, which helps them grieve beforehand and process the loss:

> *Therefore, seeing death as natural, as part of life, can help - at least I think it helped me and my parents - to face this … normal outcome, which happens with everything in life* (FCG 2; II)

Our study led us reflect on the various meanings that caregivers may assign to death and to this process (i.e., some struggle coping with it but others are able to talk openly about death as a coping strategy). Therefore, it could be beneficial to provide caregivers with a family and psycho-educative-based intervention prior to the death of the patient (Hebert et al., 2006) and to offer easier access to information and support. It might help them make sense of this complicated period and in dealing with the pain and suffering associated with their experience.

3.5. Caregivers’ resources and strengths

Amidst the complexities underlying the caregiving of cancer patients in the context of palliative care, it was just as important to acknowledge the array of positive experiences and strengths emphasized by these caregivers during the focus groups. This section sheds light on the constructive interactions they encountered and the sources of support that contributed positively to their caregiving journey.

One of the highlighted strengths was the positive experiences with health professionals (total of 42 references), both as emotional or other kind of support, mental health access, kindness, or information sharing. Feeling validated and supported was a cornerstone to this period, one in which many caregivers enter with no prior experience or training to assist them with the daily tasks they will be expected to perform (Oliveira et al., 2024). Family caregivers consistently underscored the importance of these interactions with healthcare professionals: they expressed profound appreciation for the emotional support, validation and empathy they received from palliative care teams. They even reported the “love” they felt:

> *I love [*husband’s name*]’s doctors, I love them all! They’re all amazing! They’re all super kind with us! I say "with us" because they’re also VERY sweet to me!* (FCG 2; III)

> *But with him I'm lucky that the neurologist who's been treating him for a few years now at [*name of hospital*], gave me her personal phone number, which I can call whenever he's having difficulties. And that's really something* (FCG 1; IV)

This provision of both emotional and other support not only validated the caregivers' feelings but also offered a crucial outlet for their own well-being.

A noteworthy dimension that we also identified from the discussions was the access to specialized mental health services. Even though some reported that they would have liked to have more regular appointments, family caregivers found comfort in the availability of these services, enabling them to navigate the psychosocial challenges they experience, labeling them as one the most important tools to help them continue their role. The integration of mental health resources into the palliative care framework not only acknowledged the emotional toll of caregiving but also equipped the caregivers, in line with their perceived needs (Marcotte et al., 2019), with strategies to cope effectively with their own mental and emotional well-being, as they also are impacted by patients' mental health (Jansen et al., 2021). This result is not a surprise as previous studies (Areia et al., 2019) already emphasize the high prevalence of psychological morbidity in family caregivers of individuals with cancer receiving palliative care who tend to defer their emotional response.

> *About the psychologist, for me it's fantastic! Sometimes I come in and think I'm not going to say anything, and I always say a lot [laughs]! And I leave feeling lighter, (…) It's fantastic for me! Being able to talk about it openly* …. (FCG 2; IV)

Participants highlighted instances where healthcare providers went above and beyond their clinical responsibilities to demonstrate genuine care and compassion. These acts of kindness were perceived as small gestures with significant emotional resonance.

> *(…) they were constantly giving me information, everything I needed. In fact, if I wanted to call or thought about calling, before I called, I already had information from them, the nurses, the doctors, the psychologist too. In terms of communication, I think it was excellent! (…) I even thought it was a bit unusual, right? (…) So much care, at a time when nobody cared about anything.* (FCG 1; I)

The second main category of strengths identified was a virtuous circle of positive impact of palliative care on the overall well-being of patients and, consequently, on the well-being of caregivers: if the patient is ok, the caregiver is also ok. The opposite is also true: according to the research (Given et al., 2004), there is an association between the increasing number of patient symptoms reported by the caregivers and the level of depressive symptoms in the same caregiver, which makes it more likely that caregivers react to the situation in ways that contribute to burden and depression. There is a remarkable satisfaction that stems from knowing about the patients' well-being which, along with the need for information, is one of the most identified needs by caregivers (Areia, Major & Relvas, 2017). Therefore, when caregivers have a positive perception of the patients' well-being, they are more likely to report feeling well themselves, as one female caregiver stated "[it] *gives you more strength to keep going and carry on day after day*" (FCG 2; III).

> *He entered* [the institution] *and initially he was very happy! I was even happier to see how happy he was because he was treated very well, he was so well received. He almost felt like he was in a hotel! (…) He was fine, and I was better* (FCG 1; I)

Caregivers also mentioned the essential opportunity for both patients and caregivers to engage in a process of emotional closure and preparation for the inevitable impending loss (Rolland, 2018) – we named this category "anticipatory grief" and it was the third most coded in this topic of the positive outlook for the caregiving experience. The focus group conversations revealed that caregivers found solace when they had the chance to engage in candid discussions about impending farewells, fears, their own pain, unburdening themselves of unvoiced feelings and sharing them with those who lived or are experiencing similar situations or even with the healthcare team.

> *I brought the family together, it was a joy for him, but he noticed as if to say, "You never did! You were always worried about Covid!" And my children came, they were there, it was a joy, but my son (…) he sensed it straight away and he said "Oh mom, why are you doing this?" – "Look, I'll tell you the truth, I don't know if he'll be here next year". And that's it! (smiles)* (FCG 3; II)
>
> *Sometimes we even talk openly about many topics, (…)*
>
> *Giving my mother the opportunity to talk about it with several people is important. Openly, to make it feel normal.* (FCG 2; IV)

Finally, central to the mesh of positive experiences within this caregiving journey is the intricate thread of "sense of belonging". "*After all, we're not the only ones suffering!*" (FCCG 3; II), as one female caregiver said. "*To find meaning in life is a fundamental aspect of human nature*" (Lambert et al., 2013, p. 1419), especially if we are in pain. As Lambert et al. (2013) concluded, how an individual perceives their sense of belonging is important for how meaningful they perceive their life. Therefore, despite their circumstances, the sense of belonging reported by the caregivers and identified in these focus groups emerges an important resource not only for people's present, but also for their future and their appreciation of the meaning of life. Thus, this category occasionally included references to the participation in the focus groups or even to the new perspective that these focus groups promoted:

> *And sometimes listen to others! Yes, it's like "I could do it this way"* (FCG 1; II)
>
> *To know that there are others, that one person is not alone, or abandoned, that the problem isn't just mine, it belongs to many people! I think that lightens the heart a bit, doesn't it? And the way I deal with it, because I'm not the only one* … (FCG 1; I)

This finding is important as it indicates that group interventions might promote a sense of belonging to caregivers, highlighting their resources and strengths and, ultimately, adding to their well-being and quality of life.

In fact, the recognition of these positive facets underscores the significance of fostering a supportive caregiving environment that acknowledges and amplifies these strengths, contributing to better caregivers' mental health and, ultimately, increasing the overall quality of care for end-of-life cancer patients and their families.

3.6. *Strengths and limitations of the study*

In the present study, participants share common experiences, specifically the emotionally intense experience of caring for a cancer patient in palliative care. Thus, if a safe space is created, in particular if participants share common intense experiences, and if they feel validated by the group members, caregivers tend to share details about their experiences (Wilkinson, 1998), creating a sense of belonging and sometimes helping to "normalize" group members' experiences. Caregivers, through their engagement in the focus group discussions, articulated a profound recognition that they were not going through their caregiving odyssey alone. Rather, they found solace and validation in the awareness that their experiences, emotions, and challenges were mirrored by others facing similar circumstances. Despite the length of our sample, we had participants from different backgrounds, namely with different work status and from different cities which we believe added richness and diversity to the interviews.

This study is not without limitations so caution should be taken when generalizing results of this study. Despite the strengths of the chosen methodology some findings might be related to participants' characteristics. For instance, this space was an opportunity for people to listen to others in a similar situation. This is a positive aspect as it allows people to examine their individual situation from another perspective. However, it can be a limitation when it hinders people from sharing an opposing opinion and skews the narrative of other participants. Regarding limitations, sometimes there are less inhibited members in the group who tend to share the greatest number of individual experiences (Wilkinson, 1998). To balance this, it was the researcher's role to moderate the conversation. In addition, the 4 focus groups included a very small number of participants. Despite the sensitive and personal nature of the topic and the Covid-19 pandemic restrictions, we were not expecting such small groups. Potential reasons to explain this are: 1) the fact that some relatives of caregivers died near the arranged date so they were not emotionally available to participate; 2) focus groups began in 2021 during a considerable outbreak of Covid-19 in Portugal, which might impact involvement; and 3) due to Covid-19, the groups were conducted via Zoom, thus we were thereby excluding participants, without Internet access or skills to enter the Zoom meeting. Also, considering this pandemic period, some institutions were overloaded with work, mainly due to staff shortages associated with Covid-19 hospitalizations. Despite this, we opted to maintain the focus group format, even with reduced sizes, due to the value of the welcoming environment and the depth of the narratives obtained.

Future investigations could try to replicate our study with an increased number of participants in the focus groups. The optimal number for a focus group typically ranges from 6 to 12 individuals. This is considered ideal for promoting diverse perspectives and facilitating meaningful group interaction. Having too few participants may limit the diversity of opinions; however, having too many can also make it challenging for everyone to actively contribute to the discussion, which was an advantage of our study.

4. Conclusions

The Portuguese strategic plan for the development of palliative care 2021–2022 (Comissão Nacional de Cuidados Paliativos, 2021) provides for the development of specialized support responses for caregivers, yet despite the prevalence of relational, emotional, financial, and family struggles, emotional support is not usually offered until the terminal stage of the illness, leaving professionals with only a short period of time to address main issues with the patient, the caregiver and the whole family. Despite the theoretical definition of this approach, in Portugal, like in many other countries, it appears out-of-reach for most of the population (Neto, 2020) or only applied when "*there is nothing left to do*" – something we often hear when, in fact, we can always provide comfort, dignity, and quality of life to patients and families. Therefore, this study is one step further to avert family burdening during these challenging times. It gives greater insight into the caregivers' experience during the terminal stage of their loved-one's illness, which allows clinicians to contemplate on effective ways to intervene with this population in these Portuguese palliative care settings, considering people's needs and strengths. The ultimate goal is for caregivers to continue to be effective in their role without compromising their own health and well-being (Northouse et al., 2012), neither before nor after the relative passes. Furthermore, these focus groups were an inspiration for thinking about palliative care interventions through different lenses, while showing that collective moments can be significant contexts for sharing and creating a sense of belonging.

To conclude, this qualitative study underscores the importance of acknowledging and alleviating the exhaustion endured by family caregivers and their suffering, along with addressing communication issues in end-of-life and other critical obstacles as they navigate the challenges of providing palliative care to their loved ones, and empowering caregivers and families boosting their resources and strengths. Our insights advocate for policy measures that recognize and address the mental and emotional well-being of caregivers, offering support mechanisms tailored to their needs.

CRediT authorship contribution statement

Carolina Oliveira: Writing – original draft, Visualization, Software, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation. **Isabel C. Lisboa:** Writing – review & editing, Validation, Software, Formal analysis. **Luciana Sotero:** Writing – review & editing, Validation, Supervision, Conceptualization. **Ana Paula Relvas:** Writing – review & editing, Validation, Supervision, Conceptualization.

Declaration of competing interest

No conflict of interest declared.

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