



Needs-focused interventions for family caregivers of older adults with cancer: a descriptive interpretive study

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Abstract

Purpose Although family caregivers (FCs) of older adults with cancer (OACs) provide invaluable assistance by fulfilling multiple tasks along the cancer trajectory, evidence suggests that their needs are poorly assessed, and there is a scarcity of supportive interventions that influence their well-being. Viewing these issues as opportunities for improvement, we conducted this qualitative study to understand FCs' needs and identify promising needs-focused interventions.

Methods This descriptive interpretive qualitative study was conducted in Quebec, Canada, in a French Canadian Oncology Clinic. Participants were FCs who were spouses or adult children ($n = 25$) of OACs aged 70 years or older. Data were collected via focus groups and were analyzed using an ongoing analytic process following each interview.

Results Three types of needs were of particular importance: information, relationships between FC and others, and care for oneself. The need for information was described in terms of the content, timeliness, and modalities in which information should be verbalized and delivered. The need for relationships specifically targeted health care providers (HCPs), family members, and OACs. The need to care for oneself was recognized as important throughout the cancer trajectory but also represented a challenge. Participants proposed innovative ideas for interventions, resources, and strategies for each type of need.

Conclusions According to our results, HCPs should systematically include FCs into OACs' care plan through the use of concrete actions such as the “family systems approach” suggested by Duhamel, and integrate a systematic FC's needs assessment.

Keywords Family caregivers · Older adults · Cancer · Oncology · Needs · Interventions

Introduction

The family caregivers (caregivers in the following text) of older adults with cancer (OACs, aged ≥ 70 years) are

considered an important part of the healthcare team [1–3]. Although the caregiver role can be rewarding, it can also be overwhelming and stressful [4]. Caring for OACs is demanding because they might experience greater challenges in coping with the cancer than younger adults [5, 6] related to comorbidities, functional decline, and reduced tolerance to treatments [7, 8]. Caregivers are involved 24/7 in providing physical care, psychological, and social aid to OACs [2, 9, 10]. They continuously adjust to changes in the OAC's state that evolves over time with related care requirements [3]. Although caregivers typically endorse these responsibilities, studies show that caregivers have insufficient education and support, feel ill prepared, and lack self-competency [1, 3, 4, 9, 11, 12]. Caregiving may result in loss of self-identity, lower levels of self-esteem, feelings of uncertainty, less self-acceptance, and a sense of being ineffective or lacking control [13]. Being a caregiver of an OAC has been described as “blurry mixture [...], a patchwork of moments of vivid intensity and compassion that at times lapse into blandness and despair” [13]. Caregivers may have more unmet needs than the relative they care for [14] and are primarily considering the cancer

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patient needs rather than their own [15]. There is cumulative evidence that caregivers for OACs experience high rates of anxiety, distress, and depression, and that the perceived burden of caregiving increases as the OAC's functional status decline [14]. Studies identify a diversity of caregiver's needs across different domains (such as information, relationships, caring, instrumental activities, spirituality, and finances [1, 2, 12, 16–18]) that are not well addressed by health care providers (HCPs) [1, 2, 19, 20]. According to Sklenarova et al. [21], predicting caregivers' unmet needs based on sociodemographic or medical conditions are limited. They found no association between age, sex, or type of relationship and the number of caregivers' unmet needs. Their study shows distress and anxiety scores to be poor predictors of unmet needs. Additionally, the diversity of research methods, the heterogeneity of participants from various countries, and the lack of precise description of interventions in the studies strongly call for further research. The conceptualization of multifaceted dimensions of caregivers' unmet needs remains to be clarified in order to reduce the scarcity of comprehensive tailored interventions for caregivers that negatively influences their health status and well-being [9, 11, 19].

The study objectives are twofold: (1) to understand caregivers' needs in caring for OACs and (2) to identify their suggestions for interventions that might address these needs.

Methods

This was a qualitative study with a descriptive and interpretive design [22]. This design was adopted as it can be helpful in understanding complex issues related to care, and obtain a richer understanding of caregivers' needs and interventions to meet them [16].

Participants

Caregivers were recruited from an ambulatory cancer clinic of an academic hospital. OACs were first approached during the recruitment process by designated HCPs, after being trained by the first author (JM) regarding caregiver's eligibility criteria: (1) a spouse or adult children of the OAC, (2) at least 3 months as a caregiver, (3) French fluency. Of the 211 OACs who were approached, 61 (28.9%) of them agreed to be contacted and referred their caregiver. Then, 15 out of 35 spouses (42.9%) and 10 out of 26 adult children (38.5%) decided to participate. Primary reasons for declining study participation from spouses were as follows: not wanting to leave the OAC alone, not wanting to tell their personal story, not having transportation, not having a good health. Whereas, adult children who refused to participate argued: not having enough availability, wanting to spend time with family, not wanting to tell their personal story.

Data collection

Three 2-h focus groups (FGs) were held between March and May 2015. The first two FGs consisted of homogeneous groups, so participants could feel comfortable sharing their experience as they would have the same relationship with the OAC: 8 patients' spouses and 7 adult children. FGs were structured with a vignette which was a fictive story describing the experience of a caregiver during a cancer trajectory: investigation of signs and symptoms, cancer diagnosis, treatments, hospitalization, and post-treatment [23]. Participants were asked to describe the caregiver's needs and suggest supportive interventions. The third FG (7 patients' spouses and 3 adult children) was based on our analysis of the two previous FGs and contained a mixed group of participants to confirm or differentiate what had been previously described. FGs were audiotaped and transcribed. Participants also answered eight demographic questions. Constant rigor was assured throughout the FGs [24] with appropriate use of the vignette to systematize data and a sufficient number of participants according to Thorne [22]. Furthermore, field notes were taken during FG followed by reflexive diary to note feelings and observations in order to stay as close to participants' perspectives as possible [22], which were used as a summary of the interview.

Data analysis

We conducted a thematic analysis of the verbatim transcripts and field notes [22] using QDA miner 4 software [25]. A constant comparative analysis method was used, which allowed each subsequent FG to be improved based on the analysis of previous interviews in order to further elucidate the details and provide greater precision for the expressed needs and interventions [22]. The first coding cycle involved deriving the emergent themes, followed by creating matrices and graphs linking needs and suggested interventions. All authors participated in this inductive approach. Analysis of the data, done by all authors, is also a strength since the researchers had different views and past experiences with this clientele. In case of discrepancies, a discussion between the researchers was planned, until there was consensus. The authors were involved in every step of data collection and analysis: vignette redaction, FGs' organization and interviews, verbatim analysis, and results redaction.

Results

Participants' characteristics

Table 1 presents the participants' characteristics. All were white French-speaking native Canadians and had children.

Table 1 Participants' characteristics ($n = 25$)

		Spouses ($n = 15$)	Adult children ($n = 10$)
Age	(Average years)	72	51
Gender	Female	12	7
	Male	3	3
Education level	High school	6	2
	2-year college degree	4	3
	3 + years university degree	5	5
Employment	(Average hours/week)	0	37
Civil status	Married	15	9
	Divorced	0	1
Children age*	(Range years)	41–50	11–30
OACs' cancer treatment	Chemotherapy	15	9
	Radiotherapy	3	2
Length of time since caregivers' involvement in OACs' care	(Average months)	13	8

*All caregivers had children (spouses and adult children). This question refers to the age of their children

Most of them were female, married, and had experienced a caregiver's role in the past year for between 8 and 13 months.

Findings

The results show that caregivers' needs can fluctuate across the cancer trajectory depending on their health status, the patient's health, the health care team's attitude, and the available services. These needs coalesced into three themes: information, relationships between caregiver and others, and care for oneself, each of which had constituent subthemes. Caregivers' needs could be experienced multiple times along the cancer trajectory and be interrelated. Participants also proposed many innovative ideas concerning interventions, resources, services, and strategies for addressing the described needs. A single intervention could meet more than one need at a time. Figure 1 illustrates the interrelatedness of the caregivers' needs and interventions according to our results.

In the following section, the expressed needs and proposed interventions are described. Tables 2, 3, and 4 present participants' quotations for each need theme.

Information

Participants communicated their information needs via two subthemes: "along the cancer trajectory" and "during hospitalization." Table 2 shows the illustrative quotations.

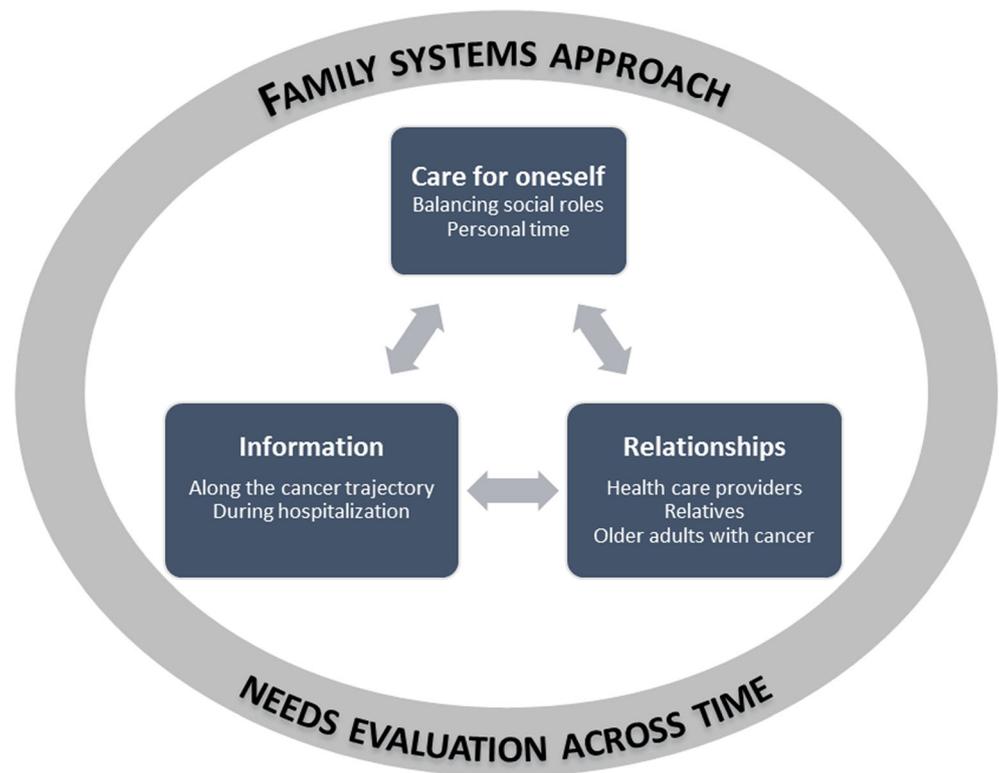
1. Along the cancer trajectory

Caregivers verbalized their need for more information about what is expected from them as a caregiver from HCPs' perspectives. Caregivers also wanted to know what they could do as caregivers to improve the OACs' chances

of recovery. They clearly viewed their own involvement as a source of support to ensure a positive outcome—namely, easing the OAC's cancer treatment experience or saving his/her life. Furthermore, caregivers wanted more detailed explanation of the care that they must perform for the OAC. Some tasks related to nursing care, such as the application of a prescribed ointment or possible side effects related to the cancer, were never explained by HCPs. So, caregivers had to perform these tasks alone at home, without knowledge and support. Sometimes, they had to execute unfamiliar tasks that had direct impacts on respecting OACs' intimacy. They expressed that they had insufficient knowledge about how to be with the OAC during such intimate moments.

Participants expressed a desire to understand OACs' diagnosis and were eager to acquire more general knowledge regarding cancer. One helpful intervention, already exercised by some caregivers, was attending an information session before OACs' treatments. This was beneficial in that it gave them a general idea about what was going to happen along the cancer trajectory. Furthermore, HCPs should always explain or define medical terms clearly in plain language. Information should also be delivered within an adequate context. Caregivers suggested that it would be helpful to receive a written summary of shared information after each appointment to improve information retention and comprehension. They could then focus on understanding the information during the meeting instead of trying to remember it, and could rely on something meaningful after returning home. In addition, caregivers verbalized their need to know what support was available to them. Community resources should be more visible in outpatient clinics and should be discussed by HCPs so that caregivers know where and how to access them. They

Fig. 1 Graphical representation of the interrelatedness of the caregivers' needs and interventions



also suggested a telephone service to which they could refer in case of unexpected health events.

Several participants stated that they wanted to discuss survivorship issues, such as what would happen following cancer treatment and surveillance of recurrence. They also wanted to receive updated information from HCPs regarding the cancer progression. Caregivers silently thought about it, but often refrained from voicing questions to “protect” OACs, who might find the subject too stressful. However, if the OAC’s death was near, they wanted to get the palliative care team involved as soon as possible to obtain adequate information and support. All participants agreed on the need for accurate and timely information along the cancer trajectory.

2. During hospitalization

Caregivers wanted up-to-date information on daily hospital activities during OACs’ hospitalization. This was particularly true for adult children, who often had a limited presence due to their various obligations at work and home. Some participants suggested they had to refer to the OACs’ chart to update their own information. Other caregivers blamed the inconsistent and ambiguous information from nurses working on different shifts and between different HCPs, and the lack of information reported by HCPs in patients’ charts. As a solution, one caregiver proposed a summary sheet containing essential information to obtain overviews of OACs’ days with different HCPs. Another caregiver suggested that caregivers should be able to plan an appointment with the doctor

during OACs’ hospitalization, which would allow them to manage their schedule and have direct contact with HCPs to answer their questions.

Relationships between caregiver and others

Caregivers described three subthemes regarding their relationship needs: HCPs, relatives, and the OACs. Table 3 shows the illustrative quotations.

1. Health care providers

Caregivers believed that they are an extension of HCPs outside the hospital. Hence, they wanted to be more involved in the care decision-making process for the OAC as they feel that they know the patient best. Furthermore, caregivers declared that they wanted their involvement to be recognized and respected. To do so, HCPs should evaluate what tasks caregivers are ready to take part in, as some could be more difficult for caregivers. For instance, some tasks demand unlimited involvement, thus reducing their ability to fulfill other social obligations. For that reason, caregivers would like HCPs to be accommodating in patients’ care. For example, meetings for blood tests, treatments, dressing changes, and consultations with HCPs should be scheduled, as much as possible, on a single day instead of being spread out throughout the week. This would prevent work absenteeism for the adult children of OACs or their neglect of other social or familial responsibilities.

Table 2 Information: illustrative quotations

Along the cancer trajectory

Needs

Caregiver's role

- “I would like more details about what I am involved in? [...] Specialists, they know about it [cancer], and how they will proceed. But us, we do not know. We know nothing!” (spouse, female)
- “Is there something I can do to increase the chances of its [treatment] success? Are there things I can do?” (adult child, female)

Care for the OAC

- “Yes, I had a little tube filled with cream but I wanted to know how to apply it [...] Did I have to put some on his penis, and testicles? Was it dangerous? Could it burn him?” (spouse, female)
- “We do not talk about the side effects that the parent can actually experience. It's at home that, sometimes, she falls, she vomits, she has diarrhea right next to the toilet. These are tangible things [...] that affect the entire family” (adult child, female)
- “To do his personal hygiene, that is so humiliating for him. He has no other choice to let me wash his buttocks. That's what I assume when he is rude with me” (spouse, female)

After the treatments

- “The cancer progresses, but we know it only at the end. When are we supposed to talk about funeral arrangements? When do we address this? We need to talk about it! [...] Where? When? How?” (spouse, female)

Interventions

- “As soon as we started to come to the oncology clinic, they told us to go to the information session. It lasted for a couple of hours. It was helpful because it reduced our fear. I know others who did not have this chance. They only got books and pamphlets and had to manage with that. Us, we had a nurse for two hours. She explained in general what we were about to live and I found it well explained.” (spouse, female)
- “I wanted to know, what is a ‘metastasis’? Is it as big as the head of a needle? Does it obstruct everything? [...] I do not know. How does it spread? Is it like a spider with its web? I do not know anything in this field” (adult child, female)
- “I think there's the context and that's what is missing. Improve the context. To communicate, that's one thing, but to have a context that is good for communication, that's another thing. To prepare, to say: ‘We will have a meeting [...] so the people who want to be there can be [...] This meeting must be in a formal context and human, so you can get information, and you have time to ask questions’ (spouse, male)
- “Why do not you give a summary paper? Something simple, [that's] already framed. ‘Cancer,’ you tick off. ‘Success rates, 10-20-40-50-70%,’ you tick off. ‘Side effects,’ you tick off. Then, you go home and you do not argue. It's clear.” (adult child, female)
- “Having the possibility of a phone call with the oncology pivot nurse*. To say: ‘I am so helpless, I do not know what to do! Can you help me?’ That would be adequate for the caregiver.” (adult child, male)

During hospitalization

Needs

- “They might say: ‘Do not worry, we will write down what happened today and let you know.’ You come back in the evening and nurses know nothing. There has been a change of shift: ‘Oh!... Who's your father again?’” (adult child, female)

Interventions

- “I would have liked a summarized fact sheet about his day [on the hospitalized floor]. You come during evening visit hours, you read: ‘The physiotherapist did an evaluation. The oncologist came, this is his name, he judges that your father's health is so and so.’ At least, I would know something because at the moment, nurses know nothing when I speak to them” (adult child, female)
- “I think what's missing is someone who says: ‘Come between 12:00 and 15:00. We will organize ourselves, and you'll be able to meet and talk with the doctor.’” (adult child, male)

*Also called “nurse care navigator,” “cancer nurse navigator,” or “cancer nurse coordinator”

Most participants suggested several basic interventions to feel acknowledged by HCPs: identify themselves and their role since caregivers meet various people in white coats every day; have HCPs plan time for caregivers; and have HCPs demonstrate their interest physically with eye contact and encourage them to ask questions. HCPs should also show empathy and compassion, which ensures that caregivers can be comfortable to talk openly with them and feel supported in their experience. Finally, HCPs should pay attention to caregivers' facial expressions and acknowledge their feelings, thus ensuring that the meeting's pace is tailored to caregivers' receptivity.

2. Relatives

From the beginning of the cancer trajectory, caregivers received very little assistance from other relatives, leading to feelings of isolation and loneliness. They wanted their other family members or friends to offer more support. Furthermore, they wanted their role and sacrifices as caregivers to be acknowledged, as some of their relatives directed attention only towards the OACs. If this was not possible, they wanted to participate in peer support groups with other caregivers where they could be understood and acquire coping strategies through others' experience and encouragement. They also wanted to

Table 3 Relationship between caregiver and others: illustrative quotations

HCPs

Needs

- “I never felt I was part of the team. I rather felt like I was put aside. I was only good at and used for taking her to the hospital and assisting her at home” (adult child, male)
- “You as a nurse, you give injections, you know how it works. But my experience was different: ‘Sit in front of him, wash your hands, now, you give him his treatment’ [authoritarian tone and finger pointing] Wow! I was not prepared. I was not feeling comfortable at all” (spouse, female)

Interventions

- “We need to come the day before [the treatment] for the blood test. This is so stupid! As a family caregiver, I have to come to the hospital twice, which makes me miss two half days of work, because the blood test needs to be done before. But we all know that we can access the results within 45 minutes. This is not acceptable for a caregiver” (adult child, male)
- “They did not present themselves. So, I asked: ‘Hello? Who are you?’ I would have liked a formal greeting... ‘Oh yeah... I am doctor X’.” (adult child, female)
- “You want to know something, but he [the doctor] is writing. He might answer you, but you must keep quiet while he is writing. You have to make it quick: think fast and choose your words because you do not want to bother him” (adult child, female)
- “Me, I have an angel of a nurse who comes to my home [...] She has compassion for us. We can cry with her. We are able to tell her what we really think” (spouse, female)
- “We met one nurse [...] who talked like a robot: ‘Step 1, 2, 3, we do a blood test, you go there and come back’. She never asked: ‘How do you feel?’ She did not focus on that.” (adult child, female)

Relatives

Needs

- “For sure! You must be there. And they always ask you: ‘How’s your husband?’ But you, you do not exist. You do not exist. This is what I find difficult” (spouse, female)

Interventions

- “Meetings like Alcoholics Anonymous, but for Family Caregivers, the FC [...] [This would allow us] to talk about our personal experience, and to acknowledge that we are not alone. Maybe we’ll get support from others. Support we do not have with our relatives” (spouse, female)
- “Maybe dare to ask for help. I think that’s a major issue we have. Dare to ask a friend for a two-hours break. Two hours, that’s nothing, but it can make a huge difference. We need to go one step ahead, and ask. Not just wait until someone offers it. Others do not see our reality as family caregiver. I think we need to push ourselves and ask” (adult child, female)

OACs

Needs

- “You need to be courageous [...] You need to talk [with the OAC]. That’s the key to success. To speak openly and frankly” (adult child, male)

Interventions

- “I’d like that spouses [OACs] be sensitized by the doctor or pivot nurse that they must care about their loving caregiver” (spouse, female)
- “My mother, I motivated her when she said: ‘Ohhh, I do not feel good today.’ ‘Well, have you called your pivot nurse? Did you talk to her?’” (adult child, female)

develop their own assertiveness, with the support of HCPs or other caregivers in the community, to accept or ask for help from others without feeling ashamed, humiliated, weak, or disrespectful to the patient.

3. Older adults with cancer

Most of the participants voiced a need to effectively communicate with OACs to foster a harmonious relationship. This communication could be guided with the HCPs’ help, who would remind OACs to take care of their caregiver. Other caregivers said that they felt obliged to always be with the OAC, so they started to put limits on this in order to respect themselves, as the role became overwhelming. Some participants asked OACs to be more involved in their own care instead of having the caregivers participate in follow-ups with HCPs in their stead.

Care for oneself

Care for oneself was identified as a challenge, as participants often had many competing duties. Caregivers felt that their role was “a full-time job. You renounce activities that you like so can fully concentrate on your loved one with cancer. At some point, your morale goes down.” (spouse, female).

This need was articulated in two subthemes: “balancing social roles” and “having personal time.” Table 4 shows the illustrative quotations. Participants reported that the information and relationship needs had to be acceptably met for them to begin caring for themselves. Otherwise, they felt they had to engage in self-sacrifice, focusing solely on the OAC because they believed that their primary role was to be a caregiver.

Table 4 Care for oneself: illustrative quotations

Balance social roles

Needs

- “[We have a] double burden. We [caregivers] have to learn the finances, how to pay, management of the investments, how to compost [...]. We must do everything, from A to Z. We are husband and wife. We shovel snow, do grocery shopping, and on top of that we always have to listen to the loved one with cancer” (spouse, female)

Interventions

- “With the CLSC, there are many services such as the Meals-on-Wheels program. For me, it’s three times per week. Of course, you must pay, but it gives you a break” (adult child, female)
- “It could be interesting to have financial support for people who are not familiar with a budget. It could be helpful but I do not think it exists” (spouse, female)

Personal time

Needs

- “To take care of yourself? Well, you need to continue to do what you love, what makes you feel good. But you need to take the time for it.” (adult child, female)

Interventions

- “You need to have someone telling you: ‘Yes, you are a family caregiver but YOU still need to think about yourself, and YOU must take care of yourself.’” (adult child, female)
- “You want to see the psychologist alone to vent your frustration, to talk, and to express what you really feel” (spouse, female)

1. Balancing social roles

Caregivers expressed a desire to balance their social roles: work, family, and caregiving. This was important because participants said that they did not have enough time to accomplish all their duties, which had a direct impact on their quality of life. Suggested interventions included access to more support for meal preparation and obtain assistance in managing the costs of cancer care. Caregivers wanted more time to act like a caregiver instead of performing tasks that were not related directly to the OAC.

2. Personal time

Caregivers also described a need to care for themselves while they cared for OACs—in other words, they recognized a need for personal time. Some caregivers were able to think about themselves and do what they wanted to enjoy themselves. Caregivers who struggled with such assertiveness suggested getting advice or reminders from other people on how to respect their limits, so they could care for themselves and not feel guilty. Caregivers proposed obtaining support from HCPs—or more specifically, meeting with a psychologist—to help them acknowledge their involvement, acquire confidence, respect themselves, and talk freely about what they really experience as a caregiver.

Discussion

Results review

This study provides us with a better understanding of the needs of caregivers (adult children and spouses) in caring for OACs and the potential supportive interventions that they believe might help them meet these needs.

Participants verbalized a need to receive information, some of which had to be communicated at different moments along the cancer trajectory, while other details had to be communicated during the OACs’ hospitalization. As McCarthy [26] pointed out, caregivers want accurate information about the prognosis, cancer treatment, sexuality, pain management, and cancer inheritance throughout the cancer trajectory. Adams et al. [16] also affirmed that caregivers require medical services and community social support so they can refer to them whenever needed. Furthermore, participants expressed uncertainties and confusion related to their associated responsibilities as caregivers due to a lack of information and insufficient preparation of both knowledge and tasks. This was also described by Hashemi-Ghasemabadi et al. [27]. Both participants and the authors of previous studies [9, 20, 28] suggested conducting educational sessions where information is communicated. In addition, participants highlighted two specific moments that were anxiety-provoking: the hospitalization and after the cancer treatment. Information continuity can be difficult for caregivers, especially adult children, due to the multiple roles they must fill during hospitalization. Therefore, they proposed an innovative strategy in which caregivers are given a written information summary to ensure accurate follow-up of OACs’ care. As for needs after cancer treatment, Kim et al. [29] found that caregivers still experience concerns and psychological distress related to their unmet needs during various phases of survivorship. This phase should be discussed at different points along the cancer trajectory, not only near the end (i.e., the beginning of the survivorship or end-of-life phase). Caregivers also expressed a desire for clear information, including receiving explanations of medical terms and getting information in an appropriate context. These findings are congruent with those of other studies [9, 16, 17].

Caregivers clarified a need to be in a “good” relationship with people they judged important during the cancer trajectory. HCPs, relatives, and OACs can provide assistance to ease caregivers’ task burden, as well as psychological support for caregivers. As noted by McCarthy [26], caregivers felt a lack of empathy, respect, and compassion from HCPs. Laidsaar-Powell et al. [30] also reported that some HCPs excluded caregivers from discussions and demonstrated disinterest in their presence. However, participants who experienced better relationships with HCPs felt a sense of reassurance and comfort. They clearly expressed that HCPs should foster a two-way communication with them, so that HCPs can understand and respond to their needs, give them time to ask questions, and validate their understanding to promote a healthy relationship. Peer support groups with other caregivers have been suggested as a solution to fill the emotional void caused by a poor relationship with HCPs or relatives, as mentioned in previous studies [17, 27]. In fact, such groups can reduce feelings of isolation and the lack of support from relatives or HCPs. Furthermore, participants stated that the communication with OACs was difficult and wanted strategies to improve it. The program developed by Kauffmann et al. [31], which was intended to educate couples in communication-based problem solving, might be one solution, although this still needs to be evaluated. A meta-analysis [32] also concluded the necessity of psychosocial interventions for couples during the cancer experience; they did, however, note heterogeneity among the studies, which makes specific recommendations difficult. No studies have evaluated communication interventions for adult children who care for OACs.

Interestingly, caregivers acknowledged the need to care for themselves as important but admitted considering the OACs’ needs first. This finding accords with that of the study by Schmid-Büchi et al. [15]. Participants viewed their role as a safeguard, advocate, listener, and assistant for the OAC at home and during treatment, and had the goal of ensuring a more positive experience throughout the cancer trajectory. They voiced their role as being sometimes difficult and wanted to receive individual psychological support, which was also suggested by Hashemi-Ghasemabadi et al. [27]. As mentioned in several past studies [33–36], caregivers might experience a sense of interpersonal loss in being unable to care for themselves, as their involvement “gets in the way” of other social roles and personal activities. Thus, their own needs might be secondary to those of the OAC. However, study participants acknowledged the importance of allowing themselves time to store energy, so that they could be receptive to facing future challenges related to the cancer. This strategy was described by Thorsnes et al. [37] as “fighting to take care of oneself.” This finding highlights the necessity of considering caregivers all along the cancer trajectory by helping them find “time for themselves,” and encouraging them to keep their own personal activities.

This paper adds to our understanding of caregivers’ perceived needs in caring for OACs and appropriate interventions for meeting these needs in this specific population, which was previously rather limited [27, 38]. As mentioned by Given and Sherwood [3], not all interventions are effective for every caregiver. Needs assessment prior to planning and administration of interventions is essential. Moreover, Given and Sherwood highlight how important it is for HCPs to pay attention to caregivers’ needs along the cancer trajectory, as the same need could be experienced multiple times and resolved using different resources. Also, as caregivers mentioned, some interventions have the potential to meet more than one need at a time. HCPs should constantly evaluate caregivers’ needs, as they can vary among individual caregivers and across time, like which interventions are appropriate. However, few researchers have described interventions that target multiple needs at once. The “family systems approach” [39] might be one of them, which involves having HCPs recognize caregivers’ involvement and integrating it into OACs’ care plan, thus treating caregivers like they are as important as the patient himself [40].

Strengths and limitations

This study has several strengths. Compared to other studies interviewing caregivers of “older” patients with cancer, our study participants were exclusively taking care of someone diagnosed with cancer and aged 70 years and older. This study is then adding knowledge to this increasing population and provides information regarding caregivers’ needs with associated interventions that HCPs could relate on.

Nevertheless, some limitations of the present study should be considered. Data collection was based on participants’ availability, which suggests that eligible caregivers who refused to engage in one FG interview might have other needs or require different interventions not articulated by the caregivers who attended, which limits the transferability of the findings. Also, participants had specific characteristics (as presented in Table 1) and were selected from a specialized oncology center in Quebec. Accordingly, the verbalized needs and interventions must be transferred to other health settings and caregivers with precautions. Our interpretation of the data was not validated by the participants.

Conclusion and clinical implications

Caregivers of OACs experience challenges from the beginning of the investigation of cancer’s signs and symptoms to the remission or death of the OAC. HCPs can utilize our findings to better understand caregivers’ needs and how they can adapt their current practice to accommodate and support caregivers with efficient needs-tailored interventions as presented in Table 5. Caregivers who did not participate in this

Table 5 Summary of the suggestions for interventions according to the participants

Needs themes	Interventions
Information	<ul style="list-style-type: none"> -Questions to answer i. What is a caregiver? ii. What does the caregiver can do to improve the OAC's situation? iii. What kind of care does the caregiver is expected to do for the OAC? iv. How to be with the OAC to respect his/her intimacy? v. What does the OAC's diagnosis mean? vi. What is next after the cancer treatment? Discuss survivorship issues or cancer progression. vii. What is the OAC's cancer response to the treatment? viii. What hospital activities did the OAC perform during his/her hospitalization? -Information sessions along the cancer trajectory -Explanations or definition of medical terms and use of plain language -Accurate and timely information communicated within an adequate context -Written summary (during appointment or OAC's hospitalization) with any HCPs -Accessible and visible community resources discussed by HCPs -Helpline -Implication of the palliative care team -Planned appointment with the doctor during OAC's hospitalization
Relationships between caregiver and others	<ul style="list-style-type: none"> -HCPs' implication/attitude i. Identify name and role for every HCPs ii. Plan time for caregivers iii. Demonstration of interest (eye contact) and caring approach (empathy and compassion) towards caregivers iv. Involve caregivers in the care decision-making process v. Evaluate caregivers' readiness for different tasks vi. Accommodate caregivers in the patient's care -Recognize and respect caregiver's involvement -Participation in peer support groups -Help to develop assertiveness to accept or ask for help -Help from relatives -Implication of the OAC in his/her care -Help to communicate effectively
Care for oneself	<ul style="list-style-type: none"> -Help for meal preparation -Resources to manage the costs of cancer care -Development of assertiveness -Consultation with a psychologist

study might present more distress than our participants, which can explain their refusal. Thus, they might have distinct or heightened needs that must be identified in further research, so HCPs can better understand them and adapt their practice by offering needs-focused interventions. Our findings suggest that the intensity of caregiver needs appears to be greater with the care of OAC than among adults with cancer [41]. These results can be explained by the facts that the health condition of the elderly with cancer is affected by his other illnesses [41, 42], aging, and loss of functional independence, in addition to his symptoms related to the disease and treatment [3]. As a result, more support is needed from caregivers. This support

puts increased pressure on spouses who are themselves aged, and adult children who have other obligations related to their family and work [41].

According to our results, HCPs should systematically include caregivers into OACs' care plan using two-way communication, as well as better consider caregivers' presence and integrate a systematic needs assessment. As reported by Gottlieb [43], it is important to teach HCPs and to provide them ongoing education about the importance to recognize the caregiver, optimize his attitudes and skills, and consider him into the OACs' care plan through the use of concrete actions like the "family systems approach" suggested by

Duhamel [39]. On the one hand, caregivers want to be useful to HCPs during the cancer trajectory. Caregivers can contribute to patients' wellness and positive response to cancer treatments through their involvement outside of the hospital. On the other hand, they want to be recognized and considered as partners by being acknowledged, respected, and consulted. Caring for caregivers would contribute to their appreciation as caregivers and prevent them from feeling overloaded and neglected.

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Compliance with ethical standards

All procedures related to the ethical standards of the institutional research committee were respected. Protocol AA-HCLM-14-009 and consent forms were submitted and approved by the hospital ethical review board. Written informed consents were obtained from all study participants.

Conflict of interest The authors declare that they have no competing interest.

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References

- Given BA, Given CW, Sherwood PR (2012) Family and caregiver needs over the course of the cancer trajectory. *J Support Oncol* 10(2):57–64
- Ream E, Pedersen V, Oakley C, Richardson A, Taylor C, Verity R (2013) Informal carers' experiences and needs when supporting patients through chemotherapy: a mixed method study. *Eur J Cancer Care* 22(6):797–806
- Given BA, Sherwood PR (2006) Family care for the older person with cancer. *Semin Oncol Nurs* 22(1):43–50
- Northouse LL, Katapodi MC, Schafenacker AM, Weiss D (2012) The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Semin Oncol Nurs* 28(4):236–245
- Bastawrous M (2013) Caregiver burden—a critical discussion. *Int J Nurs Stud* 50(3):431–441
- Goldzweig G, Merims S, Ganon R, Peretz T, Baider L (2012) Coping and distress among spouse caregivers to older patients with cancer: an intricate path. *J Geriatr Oncol* 3(4):376–385
- Bellizzi KM, Mustian KM, Paless OG, Diefenbach M (2008) Cancer survivorship and aging. *Cancer* 113(S12):3530–3539
- Naeim A, Reuben D, Ganz P (2011) Management of cancer in the older patient. Elsevier Health Sciences, Philadelphia
- Given BA, Given CW, Sherwood PR (2012) The challenge of quality cancer care for family caregivers. *Semin Oncol Nurs* 28(4):205–212
- Gaugler JE, Given WC, Linder J, Kataria R, Tucker G, Regine WF (2008) Work, gender, and stress in family cancer caregiving. *Support Care Cancer* 16(4):347–357
- DuBenske LL, Wen K-Y, Gustafson DH, Guarnaccia CA, Cleary JF, Dinauer SK, Mctavish FM (2008) Caregivers' differing needs across key experiences of the advanced cancer disease trajectory. *Palliat Support Care* 6(3):265–272
- Northfield S, Nebauer M (2010) The caregiving journey for family members of relatives with cancer: how do they cope? *Clin J Oncol Nurs* 14(5):567–577
- Baider L, Surbone A (2014) Universality of aging: family caregivers for elderly cancer patients. *Front Psychol* 5(744):1–7
- Soothill K, Morris S, Harman J, Francis B, Thomas C, McIlmurray MB (2001) Informal carers of cancer patients: what are their unmet psychosocial needs? *Health Soc Care Community* 9(6):464–475
- Schmid-Büchi S, Halfens RJ, Dassen T, Van Den Borne B (2008) A review of psychosocial needs of breast-cancer patients and their relatives. *J Clin Nurs* 17(21):2895–2909
- Adams E, Boulton M, Watson E (2009) The information needs of partners and family members of cancer patients: a systematic literature review. *Patient Educ Couns* 77(2):179–186
- Sinfield P, Baker R, Ali S, Richardson A (2012) The needs of carers of men with prostate cancer and barriers and enablers to meeting them: a qualitative study in England. *Eur J Cancer Care* 21(4):527–534
- Molassiotis A, Wilson B, Blair S, Howe T, Cavet J (2011) Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. *Psycho-Oncology* 20(1):88–97
- Given BA, Northouse L (2011) Who cares for family caregivers of patients with cancer? *Clin J Oncol Nurs* 15(5):451–452
- Given BA, Grant M (2012) Studies of caregivers of older cancer patients needed. *J Geriatr Oncol* 3(4):295–298
- Sklenarova H, Krümpelmann A, Haun MW, Friederich HC, Huber J, Thomas M, Winkler EC, Herzog W, Hartmann M (2015) When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer* 121(9):1513–1519
- Thome S (2016) Interpretive description: qualitative research for applied practice, vol 2. Routledge Abingdon
- Miles MB, Huberman AM, Saldana J (2014) Qualitative data analysis: a methods sourcebook. In: SAGE publications Inc. Newbury Park, California
- Krueger R, Casey M (2009) Focus groups: a practical guide to applied science. In: SAGE publications Inc. Thousand Oaks, California
- Provalis Research Qualitative data analysis software. <http://provalisresearch.com/products/qualitative-data-analysis-software>
- McCarthy B (2011) Family members of patients with cancer: what they know, how they know and what they want to know. *Eur J Oncol Nurs* 15(5):428–441
- Hashemi-Ghasemabadi M, Taleghani F, Yousefy A, Kohan S (2016) Transition to the new role of caregiving for families of patients with breast cancer: a qualitative descriptive exploratory study. *Support Care Cancer* 24(3):1269–1276
- Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW (2010) Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin* 60(5):317–339
- Kim Y, Kashy DA, Spillers RL, Evans TV (2010) Needs assessment of family caregivers of cancer survivors: three cohorts comparison. *Psychooncology* 19(6):573–582. <https://doi.org/10.1002/pon.1597>
- Laisaar-Powell R, Butow P, Bu S, Fisher A, Juraskova I (2016) Attitudes and experiences of family involvement in cancer consultations: a qualitative exploration of patient and family member perspectives. *Support Care Cancer* 24(10):4131–4140
- Kauffmann R, Bitz C, Clark K, Loscalzo M, Kruper L, Vito C (2016) Addressing psychosocial needs of partners of breast cancer patients: a pilot program using social workers to improve

- communication and psychosocial support. *Support Care Cancer* 24(1):61–65
32. Badr H, Krebs P (2013) A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psychooncology* 22(8):1688–1704
 33. Haley WE (2003) Family caregivers of elderly patients with cancer: understanding and minimizing the burden of care. *J Support Oncol* 1(4 Suppl 2):25–29
 34. Öhman M, Söderberg S (2004) The experiences of close relatives living with a person with serious chronic illness. *Qual Health Res* 14(3):396–410
 35. Shaw J, Harrison J, Young J, Butow P, Sandroussi C, Martin D, Solomon M (2013) Coping with newly diagnosed upper gastrointestinal cancer: a longitudinal qualitative study of family caregivers' role perception and supportive care needs. *Support Care Cancer* 21(3):749–756
 36. Sherman DW, McGuire DB, Free D, Cheon JY (2014) A pilot study of the experience of family caregivers of patients with advanced pancreatic cancer using a mixed methods approach. *J Pain Symptom Manag* 48(3):385–399
 37. Thorsnes SL, Blindheim K, Brataas HV (2014) Next of kin of cancer patients - challenges in the situation and experiences from a next of kin course. *Eur J Oncol Nurs* 18(6):578–584
 38. Given BA (2014) Cancer in the aging: what are we doing to family caregivers? *Cancer Nurs* 37(5):402–403
 39. Duhamel F (2010) Implementing family nursing: how do we translate knowledge into clinical practice? Part II: the evolution of 20 years of teaching, research, and practice to a Center of Excellence in family nursing. *J Fam Nurs* 16(1):8–25
 40. Wright LM, Leahey M (2012) *Nurses and families: a guide to family assessment and intervention*, 6th edn. F.A. Davis, Philadelphia
 41. Hsu T, Loscalzo M, Ramani R, Forman S, Popplewell L, Clark K, Katheria V, Feng T, Strowbridge R, Rinehart R, Smith D, Matthews K, Dillehunt J, Hurria A (2014) Factors associated with high burden in caregivers of older adults with cancer. *Cancer* 120:2927–2935
 42. Senden C, Vandecasteele T, Vandenberghe E, Versluys K, Piers R, Grypdonck M, Van Den Noortgate N (2015) The interaction between lived experiences of older patients and their family caregivers confronted with a cancer diagnosis and treatment: a qualitative study. *Int J Nurs Stud* 52:197–206
 43. Gottlieb LN (2014) *Les soins fondés sur les forces: La santé et la guérison de la personne et de la famille*. Éditions du Renouveau Pédagogique Inc, Saint-Laurent, Qc