Supportive Care in Cancer (2022) 30:9411–9419
https://doi.org/10.1007/s00520-022-07379-7

ORIGINAL ARTICLE

Unmet supportive care needs of caregivers according to medical settings of cancer patients: a cross-sectional study

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Received: 21 March 2022 / Accepted: 26 September 2022 / Published online: 7 October 2022

Abstract

Purpose The objectives of this study were to compare the unmet supportive care needs (SCN) of caregivers and describe the 10 most frequent of them according to various cancer settings: phase of cancer care pathway (i.e., treatment vs. follow-up), cancer site (i.e., breast, digestive, or lung cancer), and cancer status (i.e., metastatic vs. non-metastatic).

Methods Participants completed a self-reported questionnaire to assess their unmet SCN (SCNS-P&C). According to their cancer settings, non-parametric ANOVA or Mann–Whitney tests were performed to compare the SCNS-P&C scores. The prevalence of caregivers with unmet SCN was described using percentages.

Results Among 583 participants, 516 caregivers (88.5%) completed the SCNS-P&C questionnaire. Most patients had digestive (47.3%), non-metastatic cancer (67.6%) and were recruited during the follow-up phase (56.2%). The results revealed no significant difference in SCNS-P&C scores according to cancer settings except for caregivers of patients with metastatic cancer, who reported more unmet SCN related to health care service and information needs. The more qualitative item per item analysis seems to indicate the existence of five frequently unsatisfied SCN across situations, especially concerns about the recurrence and reduction of stress in patients, with variable ranking among the most unmet SCN.

Conclusion Although there was no significant difference in unmet SCN scores between medical settings, examining the prevalence of unmet SCN helps identify the issues to focus on when supporting caregivers and developing dedicated consultations or interventions for them.

Keywords Cancer · Caregiver · Comparison · Prevalence · Supportive care needs · Unmet needs

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Introduction

Although the major role of cancer patients' caregivers has been demonstrated, their difficulties are still underestimated both in clinical practice and in the literature. They help considerably in daily life, assisting patients with medication intake, monitoring/managing physical and psychological symptoms, and facilitating everyday life [1]. They can sometimes play a role similar to that health professionals [2]. Caregivers thus need adequate interactions with health professionals when they seek help and information or wish to receive psychosocial support [1]. However, they tend not to express their difficulties and stressors [3]. Moreover, their tendency to prioritize the patients and neglect their own lives often causes burden [4–6], which leads to a deterioration of their health, quality of life, and mental well-being [7–10]. They often suffer from emotional distress which can be greater than that of the patients themselves [7, 11–13]. Emotional distress can thus contribute to an impaired quality of life and the development of supportive care needs (SCN) [14].

Caregivers thus express SCN in many areas [15, 16]. SCN may be associated with care and information (e.g., they wish to have more information about the patients' medical situation, more opportunities to talk with professionals and receive help to better manage symptoms) and psychological and emotional experience (e.g., they need help in managing emotional distress and the fear of recurrence or death). SCN may be related to the impact of the caregiving role in daily life (e.g., they need help in finding a balance between their own needs and those of the patients), professional and social security (e.g., they need assistance for administrative tasks or obtaining financial support), and communication within the family sphere (e.g., for better communication with the patients' relatives).

Several models have considered the importance of taking into account patient-related clinical variables (e.g., patient illness-related factors) and the stage of the cancer care pathway to understand the experience of caregivers and determine critical contexts [17, 18]. The literature shows unmet SCN, emotional distress, and an impaired quality of life in caregivers at each stage of the care pathway [6, 19–24]. However, we do not know specifically which SCN are the most unmet at each stage of the care pathway and for each type of cancer (e.g., cancer site or status). Research on unmet SCN of caregivers has mainly focused on palliative care or follow-up phases [22] several years after diagnosis or after the end of treatment, without considering the type of cancer or the stage of the care pathway. Studies on the predictors of unmet needs have shown contrasting results [16], perhaps due to the characteristics of participants and the cancer care context. It therefore seems difficult to propose adapted interventions according to the main unmet SCN at each stage of the care pathway for caregivers who are most at risk of experiencing difficulties.

The first objective was thus to compare the unmet SCN of caregivers according to the stage of the care pathway (i.e., treatment vs. follow-up), cancer site (i.e., breast, digestive, or lung cancer), and cancer status (i.e., metastatic vs. non-metastatic). The second objective was to describe the 10 most frequent unmet SCN according to these various cancer settings. This descriptive aim was to identify the most frequent unmet SCN in each medical context, in order to tailor caregivers' support and develop dedicated interventions and consultations.

Methods

Participants and procedure

The participants had to be at least 18 years old and designated as the primary natural caregiver (i.e., the informal caregiver who provided the most support in daily life from the patient's perspective) by the patients with a breast, digestive, or lung cancer (i.e., the most frequent in France). They were recruited during chemotherapy or the follow-up stage until 1 year after the end of treatment. The non-inclusion criteria were having difficulty understanding written French, being psychologically or physically unable to complete questionnaire, and being under legal guardianship.

The study was explained and proposed to outpatients and their designated caregivers during a medical consultation in four cancer hospital departments in France. If the designated caregiver was not present at the time of the consultation, the patient could give the caregiver an envelope with information related to the study. After giving their written consent, caregivers received a questionnaire to complete and return to the care center. An anonymous identification number was allocated to the patients and caregivers to guarantee the conditions of anonymity and confidentiality of information. This study complied with the tenets of the Declaration of Helsinki and received the approval of the University Ethics Committee (2015–3-S35).

Measures

Participants completed a self-reported questionnaire to assess their socio-demographic characteristics (e.g., age, gender, and employment) and their unmet SCN using the Supportive Care Needs Survey for Partners and Caregivers (i.e., SCNS-P&C questionnaire) [15]. This scale is composed of 41 items corresponding to potential difficulties met by the caregivers of cancer patients. For each item, caregivers assessed their SCN on a five-point scale (i.e., 1 = no need, 2 = satisfied need, 3 = low unmet need, 4 = moderate unmet need, and 5 = high unmet needs). The scale enables four scores of SCN to be generated according to the type of needs: (1) health care service and information needs (i.e., focused on the patient's care and support), (2) emotional and psychological needs (i.e., focused on the caregiver's personal experience and needs), (3) professional and social security needs (i.e., focused on financial and administration support), and (4) communication and family support needs. In accordance with the validation of the SCNS-P&C [15], the items were re-scored on a four-point scale (i.e., 1 to 4) so that response 1 would correspond to no need or satisfied need and responses 2, 3, and 4 would correspond to low, moderate, and high unmet needs, respectively. A high score indicated a high level of unmet SCN. At least 50% of the items per dimension need to be completed in order to compute the scores considering that missing items did not differ from responded items. Data relating to patients (e.g., age and gender) and their clinical situation (e.g., type of cancer and stage of cancer care pathway) were extracted from the patients' medical records with their consent.

Statistical analysis

Baseline characteristics of the caregivers and patients were described using mean (standard deviation) and median (minimum–maximum) for quantitative variables and number and percentage for qualitative variables.

For the first objective, an ANOVA or Mann–Whitney nonparametric test was performed to compare the SCNS-P&C scores according to cancer settings (i.e., cancer site, treatment phase, and metastatic/non-metastatic cancer situation). p-values < 0.05 were considered statistically significant.

For the second objective, the prevalence of caregivers with unmet SCN was described using percentages, pooling responses 2 to 4 from the SCNS-P&C questionnaire, in order to rank the 10 most frequently unmet SCN for each cancer setting.

All analyses were performed with the SAS software (version 9.4) (SAS Institute Inc., Cary, NC, USA).

Results

Participants

Between November 2016 and May 2019, 583 caregivers participated in the study and 516 caregivers (88.5%) completed the SCNS-P&C questionnaire. Baseline characteristics of caregivers and patients are summarized in Table 1. Most caregivers were female (62.5%) and were the patient's partner (75.2%). Most patients had digestive (47.3%), non-metastatic cancer (67.6%) and were recruited during the follow-up phase until 1 year after the end of treatment (56.2%).

Table 1 Participants' socio-demographic and clinical characteristics (n = 516)

	n	%
Caregivers		
Age*	509	57.42 (13.58)
Gender		
Female	320	62.5
Male	192	37.5
Caregiver status		
Partner	386	75.2
Other**	127	24.8
Education level		
< High school diploma	152	30.2
= High school diploma	90	17.9
> High school diploma	160	31.8
None or primary school certificate	101	20.1
Employment status		
Active***	198	40.2
Inactive****	295	59.8
Health care service and information needs*	505	1.74 (0.78)
Emotional and psychological needs*	502	1.67 (0.68)
Professional and social security needs*	502	1.41 (0.66)
Communication and family support needs*	505	1.49 (0.83)
Patients		
Age*	513	61.80 (11.60)
Gender		
Female	261	50.9
Male	252	49.1
Cancer site		
Digestive	244	47.3
Lung	88	17.0
Breast	184	35.7
Treatment phase		
Chemotherapy	226	43.8
Surveillance	290	56.2
Metastases		
No	349	67.6
Yes	167	32.4
Education level		
< High school diploma	149	30.3
= High school diploma	78	15.9
> High school diploma	127	25.9
None or primary school certificate	137	27.9
Employment status		
Active***	115	25.9
Inactive****	329	74.1

*Mean (standard deviation) for continuous variables; **Friend, child, sibling, parent, and other; ***Active and student; ****Inactive, retired, or looking for employment

Comparisons of SCNS-P&C scores

The results revealed no significant difference in SCNS-P&C scores between cancer site, treatment phase, and cancer status, except for health care service and information needs score with 1.37 (range 1–4) for caregivers of patients with non-metastatic cancer and 1.67 (range 1–4) for caregivers of patients with metastatic cancer ($p = 0.017$), respectively (Tables 2 and 3).

Prevalence and ranking of the 10 most frequently unmet SCN: common findings

The 10 most frequently unmet SCN for each cancer setting according to cancer site (Fig. 1a), treatment phase (Fig. 1b), and metastatic/non-metastatic cancer status (Fig. 1c) are presented in Fig. 1. Overall, the five most frequently unmet SCN common to all cancer settings were related to health care service and information needs (i.e., reducing stress for patient, obtaining information about treatment effects, and discussing concerns with the doctor) and emotional and psychological needs (i.e., discussing concerns about cancer recurrence and feelings about death).

The two main unmet SCN were related to concerns about cancer recurrence and reduction of patient stress, regardless of the medical context. Concerns about recurrence was one of the most unmet SCN for caregivers of patients with digestive (62.8%, rank 1) or breast (57.2%, rank 1) cancer, in the chemotherapy phase (50.7%, rank 2) or in the follow-up phase (64.9%, rank 1), and for metastatic (52.5%, rank 2) and non-metastatic cancers (61.6%, rank 1). Likewise, reduction of patient stress was one of the most unmet SCN for caregivers of patients with digestive (45.8%, rank 3) or lung (56.1%, rank 1) or breast (54.8%, rank 2) cancer in the chemotherapy phase (53.4%, rank 1) or in the follow-up phase (48.6%, rank 2), and for metastatic (55.6%, rank 1) or non-metastatic cancer (48.4%, rank 2). Overall, results showed more variability in the ranking of unmet SCN according to their prevalence for cancer site than for cancer stage or for metastatic/non-metastatic cancer status.

Prevalence and ranking of the 10 most frequently unmet SCN: differences and specificities

Cancer sites

Out of the 10 most frequently unmet SCN, caregivers of patients with breast cancer tended to report more unmet SCN related to health care service and information needs than caregivers of patients with other cancers. The caregivers of patients with digestive or lung cancer seemed to report more unmet needs related to their own experience of caregiving (i.e., emotional and psychological needs) and with higher scores than caregivers of breast cancer patients:

Table 2 Description of SCNS-P&C scores according to cancer site

	Digestive ($n = 244$)			Lung ($n = 88$)			Breast ($n = 184$)			p
	n	Mean (SD)	Median (range)	*n*	Mean (SD)	Median (range)	*n*	Mean (SD)	Median (range)	
Health care service and information	240	1.70 (0.77)	1.39 (1–4)	84	1.76 (0.75)	1.61 (1–4)	181	1.78 (0.81)	1.56 (1–4)	0.593
Emotional and psychological	241	1.71 (0.71)	1.50 (1–4)	80	1.65 (0.62)	1.53 (1–4)	181	1.62 (0.67)	1.44 (1–4)	0.397
Professional and social security	238	1.40 (0.67)	1.00 (1–4)	83	1.38 (0.62)	1.00 (1–3)	181	1.43 (0.65)	1.00 (1–4)	0.841
Communication and family support	239	1.58 (0.92)	1.00 (1–4)	84	1.41 (0.79)	1.00 (1–4)	182	1.42 (0.73)	1.00 (1–4)	0.081

An ANOVA test is used unless indicated otherwise. *SD*, standard deviation

Table 3 Description of the SCNS-P&C scores by treatment phase and metastatic/non-metastatic cancer status

	Surveillance ($n = 290$)			Chemotherapy ($n = 226$)			p	Non-metastatic cancer ($n = 349$)			Metastatic cancer ($n = 167$)			p
	N	Mean (SD)	Median (range)	*N*	Mean (SD)	Median (range)		*n*	Mean (SD)	Median (range)	*n*	Mean (SD)	Median (range)	
Health care service and information	281	1.75 (0.80)	1.50 (1–4)	224	1.72 (0.76)	1.50 (1–4)	0.996	340	1.69 (0.78)	1.37 (1–4)	165	1.83 (0.78)	1.67 (1–4)	0.017
Emotional and psychological	283	1.71 (0.67)	1.56 (1–4)	219	1.62 (0.69)	1.38 (1–4)	0.086	341	1.66 (0.69)	1.50 (1–4)	161	1.68 (0.66)	1.50 (1–4)	0.526
Professional and social security	278	1.41 (0.67)	1.00 (1–4)	224	1.40 (0.64)	1.00 (1–4)	0.940	338	1.41 (0.69)	1.00 (1–4)	164	1.41 (0.59)	1.00 (1–4)	0.174
Communication and family support	281	1.53 (0.84)	1.00 (1–4)	224	1.44 (0.83)	1.00 (1–4)	0.093	340	1.52 (0.86)	1.00 (1–4)	165	1.44 (0.79)	1.00 (1–4)	0.358

A non-parametric Mann–Whitney test is used unless indicated otherwise. *SD*, standard deviation

- Caregivers of patients with digestive cancer seemed to have more dissatisfaction or difficulty with emotional and psychological needs (i.e., 5 out of 10 needs) and a specific dissatisfaction or difficulty with "balancing own and patient's needs" (42.7%, rank 6) and "decision-making in uncertainty" (40.7%, rank 10) than other cancers.
- Caregivers of patients with lung cancer reported higher scores (i.e., rank 3 to rank 6) for emotional and psychological needs but more specific dissatisfaction or difficulty with health care service and information needs related to "involved in patient care" (43.4%, rank 8) and "complaints regarding care addressed" (42.7%, rank 10) than other cancers.
- Caregivers of patients with breast cancer reported more unmet SCN related to health care service and information needs with a specific need related to "best medical care for patient" (41.9%, rank 8).

Treatment phases

Out of the 10 most frequently unmet SCN, caregivers of patients during the chemotherapy phase reported more unmet SCN related to health care service and information needs (i.e., seven out of 10 needs), while caregivers of patients during the follow-up phase seemed to focus more on their own personal needs (i.e., five emotional and psychological needs out of 10):

- Caregivers of patients during the chemotherapy phase reported more unmet SCN related to health care service and information needs with specific dissatisfaction regarding "information prognosis" (42.9%, rank 6) and "best medical care for patient" (40.8%, rank 7), unlike during the follow-up phase.
- Caregivers of patients during the follow-up phase seemed to focus more on their own personal needs (i.e., emotional and psychological needs) than during the chemotherapy phase, specifically on "look after own health" (42.7%, rank 9) and "balancing own and patient's needs" (42.6%, rank 10).

Cancer status

Out of the 10 most frequently unmet SCN, caregivers of patients with metastatic cancer reported more unmet SCN concerning patients' care (i.e., related to health care service and information needs) with stronger prevalence:

- Caregivers of patients with metastatic cancer showed specific dissatisfaction with "information alternative therapies" (49.1%, rank 6) and "involved in patient care" (46.1%, rank 9) compared to non-metastatic cancer patients.

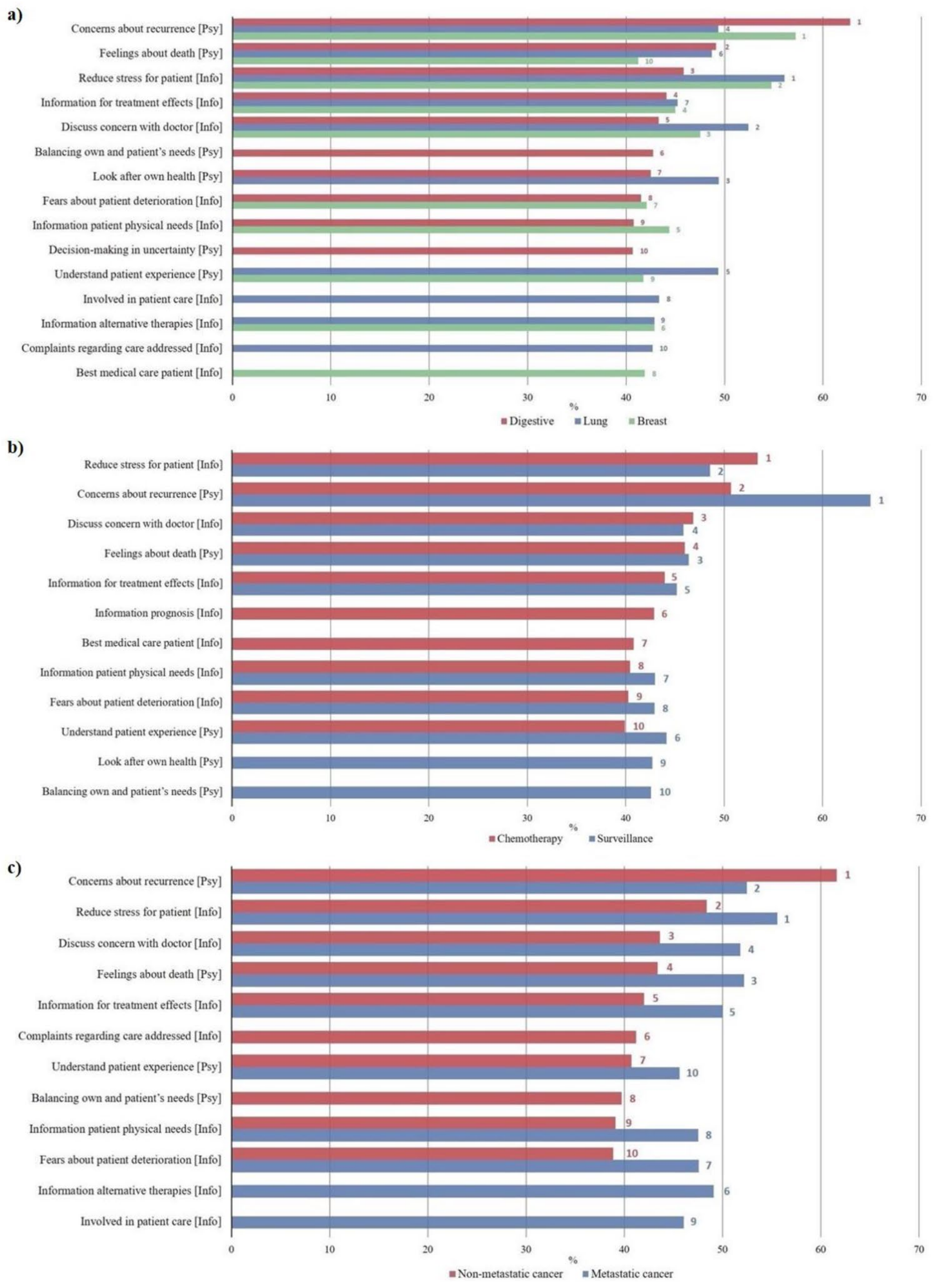

Fig. 1 Ten unmet supportive care needs according to cancer site (**a**), treatment phase (**b**), and metastatic/non-metastatic cancer status (**c**). [Psy] = emotional and psychological SCN; [Info] = health care service and information SCN

- Caregivers of patients with non-metastatic cancer showed more dissatisfaction with "complaints regarding care addressed" (41.2%, rank 6) and "balancing own and patient's needs" (39.7%, rank 8).

Discussion

The objectives of the study were to compare the unmet SCN of caregivers according to cancer settings (i.e., phase of the care pathway, cancer site, and status) and to identify the most unmet SCN for each medical setting. Caregivers were expected to report more unmet SCN in a treatment phase and in the event of metastatic cancer. Considering the side effects of treatments and the impact on survival, caregivers were likely to report more difficulties and more unmet SCN for lung cancer, then digestive cancer and finally breast cancer. Overall, no differences in SCN scores were observed between the various medical settings, showing no significant impact of cancer patients' medical contexts on the unmet SCN of caregivers, except for caregivers of metastatic cancer patients (i.e., more unmet SCN related to health care service and information). The more qualitative item per item analysis revealed that the five most frequently unmet SCN tended to be common to the various cancer situations, but that there was variability in the ranks of the 10 most unmet SCN.

Caregivers reported as many unmet SCN and difficulties during the active phase of treatment, such as chemotherapy, as during the first year of follow-up. Regardless of the patient's medical situation, it seems important to continue supporting caregivers even after treatment has ended. During this first year of follow-up, caregivers may not yet have been able to assimilate this period of life and develop resilience. They may also need more time to ease up on their caregiving role and recover from the significant impact it had on their lives. Some patients may also still experience repercussions of the disease and its treatments and still need caregiver support. It takes several years for caregivers to recover in terms of health and emotional distress and see a significant reduction in their unmet SCN [25, 26]. However, even if there was no significant difference in the scores, caregivers of patients during the chemotherapy phase reported more unmet SCN related to health care service and information needs among the 10 most frequently unmet SCN. This is concordant with previous studies showing that patients and their care are a priority for caregivers [4–6]. Their unmet SCN concern more their own experience, needs, and health during the first year of follow-up (e.g., "look after own health" and "balancing own and patient's needs"). They begin readjusting their priorities and become less involved in the medical system during the first year of follow-up than during the chemotherapy phase.

The results revealed no significant difference in SCNS-P&C scores between cancer sites (i.e., breast, lung, and digestive cancer), while the literature shows variable effects of cancer sites according to the types of supportive care needs and the time since diagnosis [15, 21, 27]. Another study showed that only the combination of anxiety and/or depression symptoms, the age of caregivers or patients, and the presence/absence of metastases predicted the risk of unmet SCN of caregivers, regardless cancer site, treatment phase, gender, or relationship to the patient [14]. Although the results showed no differences in the SCN scores between the cancer sites in the present study, the prevalence of the 10 most unmet SCN more frequently showed unmet SCN related to health care service and information needs for caregivers of breast cancer patients. These findings should be interpreted in light of variables such as specific challenges related to cancer treatments and their effects, medical care, clinical characteristics, and medical system. Indeed, the care system and in particular the overall care (e.g., medical time, nurse coordinator, and supportive care specialists) provided to patients and caregivers depending on the type of cancer can play an important role.

Only cancer status showed a significant impact on the unmet SCN of caregivers related to health care service and information needs, with more unmet SCN and greater prevalence for caregivers of metastatic cancer patients. This result is in line with several studies showing more unmet needs in palliative settings [11, 14, 16]. In this more uncertain and complex context, caregivers may need more support from professionals in caring for patients. They seem to be less involved with the medical team and to be more interested in alternative therapies. They also consider less their own personal needs and difficulties when patients are battling advanced cancers.

Finally, five SCN stand out as being the most frequently unmet in most oncological contexts. They are related to health care service and information needs (i.e., "reduce stress for patient," "information for treatment effects," and "discuss concerns with doctor") and emotional and psychological needs (i.e., "concerns about recurrence" and "feelings about death"). The two main unmet SCN are related to concerns about cancer recurrence and reduction of patient stress, regardless of the medical context, as previously showed [13, 21]. It is thus essential for caregivers to be involved in patient care, be informed and work with health care professionals, with a significant prevalence of unmet SCN related to health care service and information needs in the present study. While information is crucial for caregivers and is an established tool for fighting the disease [20, 27–29], the needs related to support from health care professionals and information are often the most unmet. Caregivers tend to prefer communication focused on each person's needs, especially their unmet information needs and those of the patients considered as two interdependent units of care [30]. Health care professionals are a major source of support for both patients and caregivers [31]. Psychological support also seems to be at the heart of caregivers' wishes to help reduce stress in both patients and themselves. As previously documented [19–21], fear of recurrence is related to one of the most frequently unmet SCN of caregivers, regardless of medical context. This confirms the importance of developing interventions based on the management of anxiety and fear of recurrence for both patients and caregivers.

The main limitation of this study is that we did not observe all oncologic contexts, which reduces the generalizability of the results. Moreover, factors other than those considered in our analyses may influence the results, such as characteristics of the samples (e.g., age of patients and caregivers) and the small size of the lung cancer group. A longitudinal approach would reinforce the validity of the results based on the cancer care pathway. Failure to consider factors related to cancer care on individual hospital wards (e.g., staff, specialists, and standard care), particularly in supportive care, may be considered a limitation. Finally, although the prevalence of unmet SCN is essential to adapt caregiver support, the most unmet SCN are not necessarily the most associated with real caregiver experience and consequently not the most significant ones [25].

Conclusion

The present study shows that caregivers experience as many unmet SCN and difficulties during cancer treatment as during the first year of follow-up, thus demonstrating the importance of continued support even after treatment has ended. Results show the necessity to better involve caregivers in patient care and inform them to reduce their difficulties, regardless of the medical context. Despite the absence of significant difference in unmet SCN between medical settings, examining the prevalence of unmet SCN indicates what to focus on when supporting caregivers and developing interventions. Results show the importance not to focus exclusively on scores of unmet SCN but to take each item into account to understand which need(s) should be considered more specifically. This study provides clues to adapt care and develop dedicated consultations for the assessment and response to caregivers' needs.

Acknowledgements We thank all participants of the PROVie study, all the investigators (especially Dr Laurent Basson, Xavier Dhalluin, Delia Muresan, Clément Gauvin, Nawale Hajjaji, Emilie Kaczmarek, Benoit Ladam, Géraldine Lauridant, Christophe Mariette, Audrey Mailliez, Camille Munck, Caroline Pagniez, Diane Pannier, David Pasquier, Arnaud Scherpereel, Marie Warniez, and Marie-Capucine Willemin), the Clinical Research Associates (especially Aline Barberio, Alexia Ciampa, Sandy Deraed, Mandy Dumortier, Emeline Duplouy, Asmaa El Fahsi, Marion Lavoisier, Danièle Leveque, Justine Lerooy, Elodie Moulinec, Laurie Parmentier, Laurence Rotsaert, Aurélie Roucou, Marie-Odile Rybczynski, Pauline Smis, Corinne Villette, Eric Wasielewski, and Fahima Yahi), Pauline Bellanger, Oceane Lefour, and Magalie Mahieuxe for their help in inclusions.

We also thank the Northwest Data Center (CTD-CNO), supported by grants from the French National League Against Cancer (LNC) and the French National Cancer Institute (INCa), for managing the data.

Author contribution A-SB, AA, and VC contributed to the study conception and design. Data collection was performed by GP, LV, AC, and TC. Material preparation and analysis of data were performed by A-SB, AA, EC, and VC. The first draft of the manuscript was written by A-SB, AA, EC, and VC. All authors read and approved the final manuscript.

Funding This work was supported by the "Comité Nord de la Ligue Contre le Cancer," ONCOLille, and received a grant from the Contrat de Plan Etat-Région CPER Cancer 2015–2020.

Availability of data and material Not applicable.

Code availability Not applicable.

Declarations

Ethics approval This study complied with the tenets of the Declaration of Helsinki and received the approval of the University Ethics Committee (2015–3-S35).

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent for publication Not applicable.

Conflict of interest The authors declare no competing interests.

References

1. Pethybridge R, Teleni L, Chan RJ (2020) How do family-caregivers of patients with advanced cancer provide symptom self-management support? A qualitative study. Eur J Oncol Nurs 48:101795. https://doi.org/10.1016/j.ejon.2020.101795
2. Ullgren H, Tsitsi T, Papastavrou E, Charalambous A (2018) How family caregivers of cancer patients manage symptoms at home: a systematic review. Int J Nurs Stud 85:68–79. https://doi.org/10.1016/j.ijnurstu.2018.05.004
3. Bodschwinna D, Ernst J, Mehnert-Theuerkauf A, Gündel H, Weißflog G, Hoenig K (2021) Dyadic coping and social support: various types of support in hematooncological patients and their spouses—associations with psychological distress. Psychooncology. https://doi.org/10.1002/pon.5631
4. García-Torres F, Jacek Jabłoński M, Gómez Solís Á, Moriana JA, Jaén-Moreno MJ, Moreno-Díaz MJ, Aranda E (2020) Social support as predictor of anxiety and depression in cancer caregivers six months after cancer diagnosis: a longitudinal study. J Clin Nurs. https://doi.org/10.1111/jocn.15123
5. 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
6. 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
7. Girgis A, Lambert S, Johnson C, Waller A, Currow D (2013) Physical, psychosocial, relationship, and economic burden of caring for people with cancer: a review. J Oncol Pract 9(4):197–202
8. Lim SM, Kim HC, Lee S (2013) Psychosocial impact of cancer patients on their family members. Cancer Res Treat 45(3):226–233. https://doi.org/10.4143/crt.2013.45.3.226
9. Northouse L, Williams A-L, Given B, McCorkle R (2012) Psychosocial care for family caregivers of patients with cancer. J Clin Oncol 30(11):1227–1234. https://doi.org/10.1200/JCO.2011.39.5798
10. Obaidi JG, Al-Atiyyat NM (2013) Quality of life among primary caregivers of women with breast cancer: a review. Middle East J Cancer 4(2):45–49
11. Friðriksdóttir N, Sævarsdóttir Þ, Halfdánardóttir SÍ, Jónsdóttir A, Magnúsdóttir H, Ólafsdóttir KL, … Gunnarsdóttir S (2011) Family members of cancer patients: needs, quality of life and symptoms of anxiety and depression. Acta Oncol 50(2):252-258
12. Jacobs J, Shaffer K, Nipp R, Fishbein J, MacDonald J, El-Jawahri A, … Greer JA (2017) Distress is interdependent in patients and caregivers with newly diagnosed incurable cancers. Ann Behav Med 51(4):519-531
13. Oberoi D, White V, Jefford M, Giles G, Bolton D, Davis I, … Hill D (2016) Caregivers' information needs and their 'experiences of care' during treatment are associated with elevated anxiety and depression: a cross-sectional study of the caregivers of renal cancer survivors. Support Care Cancer 24(10):4177-4186
14. Baudry A-S, Vanlemmens L, Anota A, Cortot A, Piessen G, Christophe V (2019) Profiles of caregivers most at risk of having unmet supportive care needs: recommendations for healthcare professionals in oncology. Eur J Oncol Nurs 43:101669. https://doi.org/10.1016/j.ejon.2019.09.010
15. Baudry A-S, Anota A, Bonnetain F, Mariette C, Christophe V (2019) Psychometric validation of the French version of the

Supportive Care Needs Survey for Partners and Caregivers of cancer patients. Eur J Cancer Care 28(1):e12896. https://doi.org/10.1111/ecc.12896

16. Lambert S, Harrison J, Smith E, Bonevski B, Carey M, Lawsin C, … Girgis A (2012) The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. BMJ Support Palliat Care 2(3):224-230
17. Fletcher B, Miaskowski C, Given B, Schumacher K (2011) The cancer family caregiving experience: an updated and expanded conceptual model. Eur J Oncol Nurs 16:387–398. https://doi.org/10.1016/j.ejon.2011.09.001
18. Kershaw T, Mood D, Newth G, Ronis D, Sanda M, Vaishampayan U, Northouse L (2008) Longitudinal analysis of a model to predict quality of life in prostate cancer patients and their spouses. Ann Behav Med 36:117–128. https://doi.org/10.1007/s12160-008-9058-3
19. Balfe M, O'Brien K, Timmons A, Butow P, O' Sullivan E, Gooberman-Hill R, Sharp L (2016) The unmet supportive care needs of long-term head and neck cancer caregivers in the extended survivorship period. J Clin Nurs 25(11–12):1576–1586. https://doi.org/10.1111/jocn.13140
20. Chen S-C, Chiou S-C, Yu C-J, Lee Y-H, Liao W-Y, Hsieh P-Y, … Lai Y-H (2016) The unmet supportive care needs—what advanced lung cancer patients' caregivers need and related factors. Support Care Cancer 24(7):2999-3009
21. Girgis A, Lambert S, McElduff P, Bonevski B, Lecathelinais C, Boyes A, Stacey F (2013) Some things change, some things stay the same: a longitudinal analysis of cancer caregivers' unmet supportive care needs. Psychooncology 22(7):1557–1564
22. Heckel L, Fennell KM, Reynolds J, Osborne RH, Chirgwin J, Botti M, … Livingston PM (2015) Unmet needs and depression among carers of people newly diagnosed with cancer. Eur J Cancer 51(14):2049-2057
23. Lee Y, Liao Y, Liao W, Shun S, Liu Y, Chan J, … Lai Y (2013) Anxiety, depression and related factors in family caregivers of newly diagnosed lung cancer patients before first treatment. Psycho-Oncology 22(11):2617-2623
24. Ream E, Pedersen VH, 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. https://doi.org/10.1111/ecc.12083
25. Lambert S, Hulbert-Williams N, Belzile E, Ciampi A, Girgis A (2018) Beyond using composite measures to analyze the effect of unmet supportive care needs on caregivers' anxiety and depression. Psychooncology. https://doi.org/10.1002/pon.4696
26. Turner D, Adams E, Boulton M, Harrison S, Khan N, Rose P, … Watson EK (2013) Partners and close family members of long-term cancer survivors: health status, psychosocial well-being and unmet supportive care needs. Psycho-Oncology 22(1):12-19
27. Chambers SK, Girgis A, Occhipinti S, Hutchinson S, Turner J, Morris B, Dunn J (2012) Psychological distress and unmet supportive care needs in cancer patients and carers who contact cancer helplines. Eur J Cancer Care 21(2):213–223
28. Sklenarova H, Krümpelmann A, Haun MW, Friederich H, Huber J, Thomas M, … 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. https://doi.org/10.1002/cncr.29223
29. Williams A, Bakitas M (2012) Cancer family caregivers: a new direction for interventions. J Palliat Med 15(7):775–783
30. Washington K, Craig K, Oliver D, Ruggeri J, Brunk S, Goldstein A, Demiris G (2019) Family caregivers' perspectives on communication with cancer care providers. J Psychosoc Oncol:1-14. https://doi.org/10.1080/07347332.2019.1624674
31. Law E, Levesque J, Lambert S, Girgis A (2018) The "sphere of care": a qualitative study of colorectal cancer patient and caregiver experiences of support within the cancer treatment setting. PLOS ONE 13. https://doi.org/10.1371/journal.pone.0209436