

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

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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, 523 caregivers (89.71%) completed the questionnaire. Most patients had digestive (47.80%), non-metastatic cancer (67.88%) and were recruited during the follow-up phase (56.21%). 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.

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 that 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), psychological and emotional experience (e.g. they need help in managing emotional distress and the fear of recurrence or death), 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) [15, 16].

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). 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. 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 by the patients (i.e. the informal caregiver who provided the most support in daily life from the patient's perspective). They were recruited during chemotherapy or the follow-up stage until one year

after the end of treatment.

The study was explained and proposed to patients and their designated caregivers during a medical consultation in four cancer hospital departments in France. After giving their consent, caregivers received a questionnaire to complete and return to the care center. 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, employment) and their unmet SCN using the 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, 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. Data relating to patients (e.g. age, gender) and their clinical situation (e.g. type of cancer, 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 non-parametric 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 523 caregivers (89.71%) completed the questionnaire. Baseline characteristics of caregivers and patients are summarized in Table 1. Most caregivers were female (62.62%) and were the patient's partner (75.00%). Most patients had digestive (47.80%), non-metastatic cancer (67.88%) and were recruited during the follow-up phase until one year after the end of treatment (56.21%).

Table 1
Participants' socio-demographic and clinical characteristics (*n* = 523).

	<i>n</i>	%
Caregivers		
Age*	516	61.00 (19–87)
Gender		
Female	325	62.62
Male	194	37.38
Caregiver status		
Partner	390	75.00
Other**	130	25.00
Education level		
< Baccalaureate degree	157	30.78
= Baccalaureate degree	90	17.65
> Baccalaureate degree	161	31.57
None or primary school certificate	102	20.00
Employment status		
Active***	201	40.28
Inactive****	298	59.72
Anxiety*	510	10.00 (0–21)
Depression*	511	6.00 (0–19)
Health care service and information needs*	505	1.50 (1–4)
Emotional and psychological needs*	502	1.50 (1–4)
Professional and social security needs*	502	1.00 (1–4)
Communication and family support needs*	505	1.00 (1–4)
Patients		
Age*	520	64.00 (22–94)
Gender		
Female	262	50.38
Male	258	49.62
Cancer site		
Digestive	250	47.80
Lung	88	16.83
Breast	185	35.37
Treatment phase		
Chemotherapy	229	43.79
Surveillance	294	56.21
Metastases		
No	355	67.88
Yes	168	32.12

*Median (range) for continuous variables; **Friend, child, sibling, parent and other; ***Active and student; ****Inactive, retired or looking for employment.

	<i>n</i>	%
Education level		
< Baccalaureate degree	152	30.52
= Baccalaureate degree	79	15.86
> Baccalaureate degree	129	25.90
None or primary school certificate	138	27.71
Employment status		
Active***	117	26.00
Inactive****	333	74.00
*Median (range) 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).

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

	Digestive (n = 256)			Lung (n = 91)			Breast (n = 236)			<i>p</i>
	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 = 334)			Chemotherapy (n = 249)			<i>p</i>	Non-metastatic cancer (n = 397)			Metastatic cancer (n = 183)			<i>p</i>
	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.

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. 1.a), treatment phase (Fig. 1.b) and metastatic/non-metastatic cancer status (Fig. 1.c) 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 (62.76%, rank 1) or breast (57.22%, rank 1) cancer in the chemotherapy phase (50.68%, rank 2), and for metastatic (52.47%, rank 2) and non-metastatic cancers (61.61%, rank 1) in the follow-up phase (64.87%, rank 1). Likewise, reduction of patient stress was one of the most unmet SCN for caregivers of patients with digestive (45.83%, rank 3) or lung (56.10%, rank 1) or breast (54.75%, rank 2) cancer in the chemotherapy phase (53.39%, rank 1) and for metastatic (55.56%, rank 1) or non-metastatic cancer (48.38%, rank 2) in the follow-up phase (48.57%, 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:

- 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" (42.74%, rank 6) and "decision-making in uncertainty" (40.69%, 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" (43.37%, rank 8) and "complaints regarding care addressed" (42.68%, 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" (41.90%, 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” (42.86%, rank 6) and “best medical care for patient” (40.81%, 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” (42.70%, rank 9) and “balancing own and patient’s needs” (42.55%, rank 10).

Cancer status

Out 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” (49.09%, rank 6) and “involved in patient care” (46.06%, rank 9) compared to non-metastatic cancer patients.
- Caregivers of patients with non-metastatic cancer showed more dissatisfaction with “complaints regarding care addressed” (41.19%, rank 6) and “balancing own and patient’s needs” (39.71%, 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. 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”, “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.

Although the results showed no differences in the SCN scores between the cancer sites in the present study (i.e. breast, lung, and digestive cancer), 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 gender of both patients and caregivers, cancer treatments and their effects, medical care and cancer status. Further analysis of the factors associated with the sample, the clinical characteristics and the medical system would provide a better understanding of these results.

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. It is thus essential for caregivers to be involved in patient care, be informed and work with healthcare 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 healthcare 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]. Healthcare 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. gender and 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. 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.

Declarations

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Authors' contributions: Anne-Sophie Baudry, Amelie Anota, and Véronique Christophe contributed to the study conception and design. Data collection was performed by Guillaume Piessen, Laurence Vanlemmens, Alexis Cortot, and Tatiana Ceban. Material preparation and analysis of data were performed by Anne-Sophie Baudry, Amelie Anota, Emilie Charton, and Véronique Christophe. The first draft of the manuscript was written by Anne-Sophie Baudry, Amelie Anota, Emilie Charton, and Véronique Christophe. All authors read and approved the final manuscript.

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: (appropriate statements regarding publishing an individual's data or image)

Not applicable

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Figures

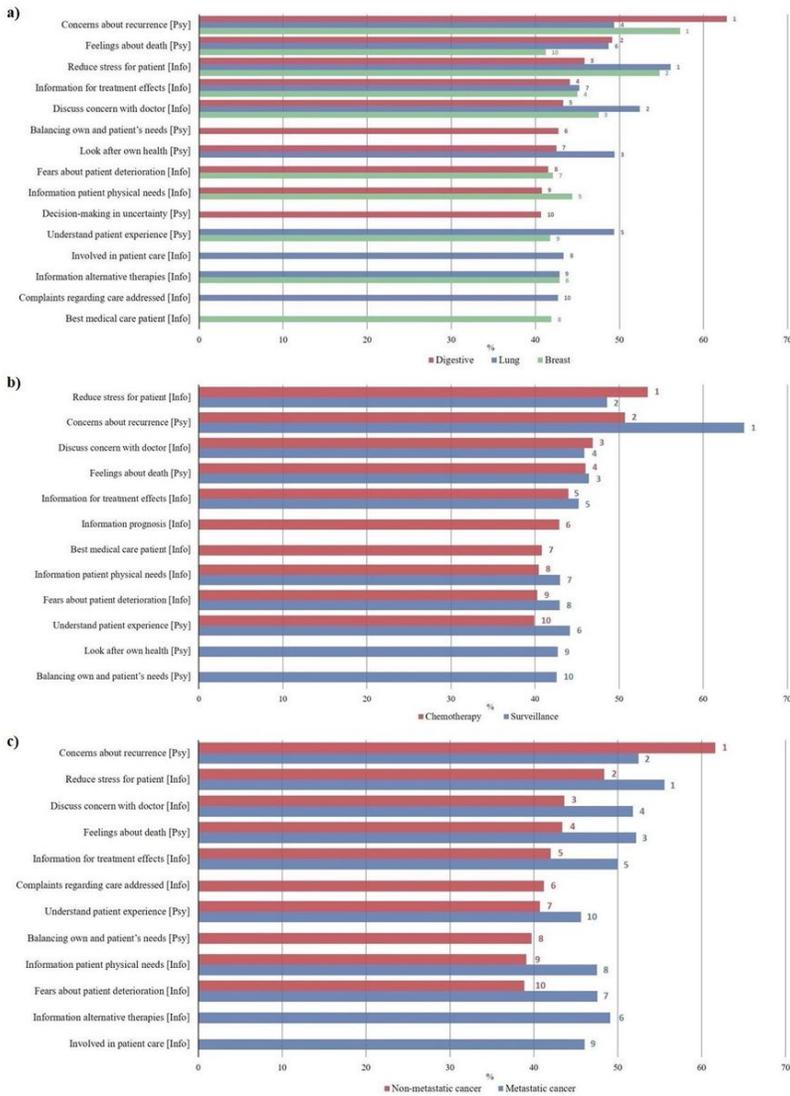


Figure 1
 10 unmet supportive care needs according to cancer site (**Fig 1.a**), treatment phase (**Fig 1.b**), and metastatic/non-metastatic cancer status (**Fig 1.c**).
 [Psy] = Emotional and psychological SCN; [Info] = Health care service and information SCN.