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Unmet care needs of patients with advanced cancer and their relatives: multicentre observational study

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ABSTRACT

Objectives The care needs of patients with advanced cancer and their relatives change throughout the disease trajectory. This study focused on the care-related problems and needs of patients with advanced cancer and their relatives. This was done from the perspective of centres for information and support.

Methods This cross-sectional study used data from the eQuiPe study: an observational cohort study in which 40 Dutch hospitals participated. All adult patients with a diagnosis of a metastasised tumour and their relatives were eligible. Measures included information on the patients' and relatives' care problems and needs, assessed by the short version of the Problems and Needs in Palliative Care questionnaire. Socioeconomic demographics were also collected.

Results 1103 patients with advanced cancer and 831 relatives were included. Both patients (M=60.3, SD=29.0) and relatives (M=59.2, SD=26.6) experienced most problems in the domain of 'psychological issues'. Both patients (M=14.0, SD=24.2) and relatives (M=17.7, SD=25.7) most frequently reported unmet needs within this domain. The most often reported unmet need by patients was 'worrying about the future of my loved ones' (22.0%); for relatives this was 'fear for physical suffering of the patient' (32.8%). There was no clear relationship between socioeconomic demographics and the experienced unmet needs.

Conclusions The most often mentioned unmet needs consisted of fears and worries, followed by a broad range of topics within multiple domains. Centres for information and support may play a role in reducing the unmet needs of (potential) visitors as these centres provide support on a broad range of topics.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Dealing with advanced cancer and its complex disease trajectory results in unmet needs of patients and their relatives.
- ⇒ Centres for information and support are installed to meet these needs and offer various types of informal care in close proximity to hospitals.

WHAT THIS STUDY ADDS

- ⇒ Not all unmet needs of patients with advanced cancer and their relatives found are 'medical' in nature.
- ⇒ The patients' and relatives' unmet non-medical needs fit the offer of centres for information and support.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ Centres for information and support have the potential of added value for both patients, their relatives and healthcare providers.
- ⇒ These centres can tailor the care provided to the personal needs of its visitors and are less restricted to limited resources and time, in contrast to formal care.

INTRODUCTION

With the development of new cancer treatments, patients with advanced cancer live longer despite the incurable metastatic conditions.[1–4] However, the prolonged experience with cancer and its treatments comes with more challenges for patients in physical, psychological, emotional and practical domains.[5 6] Examples include dealing with the side effects of the treatment,[7] problems in social engagement,[8] sleep disturbances,[9] anxiety and depression,[10] and impairment of the usual day-to-day functioning. Patients with advanced cancer wish to live their lives normally and, at the same time, they are aware of their closeness to death.[11] Understanding what can be expected during the trajectory may help in coping with the disease.[12] The complex and changing disease trajectory of advanced cancer and the consequences thereof may also result in fluctuating care needs in patients with advanced cancer.

Not only patients, but also informal caregivers, for example, spouses, relatives and friends experience the burden of the disease trajectory.[13] Informal caregivers take major responsibilities in the caretaking of the patient, providing emotional support and, together with the patient, they face uncertainties across the whole treatment trajectory in terms of the disease's prognosis and progression. The nature of this long-term caregiving is challenging for informal caregivers, and, as a result, they can suffer from a wide range of unmet needs, even when they do not regard caregiving as a burden.[14]

Substantial research focused on the unmet care needs of patients with advanced cancer and their informal caregivers, including a recent review study.[15] The review by Hart *et al* included 81 studies and identified multiple unmet need domains in patients and their caregivers. Patients reported the highest unmet needs in 'financial', 'health system and information', 'psychological', and 'physical and daily living' domains, whereas caregivers reported the highest unmet needs in the domains of psychological issues, and the domain of 'patient care and support', including illness, treatment and care-related information. Moreover, another study showed that the unmet needs of patients are associated with physical symptoms, anxiety and a diminished quality of life (QoL), and that caregivers report higher levels of unmet needs when patients suffer from anxiety, depression or low physical performance.[16] Hence, the unmet needs of patients with advanced cancer can increase the level of their caregivers' experienced burden.[17–20] Therefore, both the needs of patients with advanced cancer and those of their relatives should be addressed.

These needs can be addressed via multiple routes. Traditionally, patients with cancer and their relatives receive care from healthcare professionals, via 'formal' care routes. 'Informal' care can also play a role, and is defined as: 'unpaid care and may involve a variety of actions, like transport to doctors, social companionship, emotional guidance or help with arranging professional care'.[21] Informal care is usually provided by family members and friends, volunteers, or via 'peer-support'. Several studies have shown that such informal care benefits coping with the psychosocial impact and practical issues of living with cancer in patients and their relatives.[22–26]

A combination of non-medical formal and informal supportive care can also be arranged by hospitals, or by initiatives that work closely together with hospitals or health-related institutes (so-called 'centres for information and support'). In that case, such care can be complementary to medical formal care that is provided by the hospital. Examples of the informal care provided by such centres include the provision of company and a listening ear by trained volunteers, the opportunity to meet peers and share experiences, and to attend creative workshops. In these centres, trained healthcare providers, working as support consultants, may offer information and advice on non-medical matters, including emotions, sexuality, relationships and work. In case targeted referral to medical care is indicated, the support consultants assist the patient in this referral process as they cooperate together with healthcare professionals within and outside the hospital.[27]

A recently published review concluded that initiatives combining non-medical formal and informal supportive care (centres for information and support) hold the potential of added value in terms of providing emotional support for, and providing information to, patients with cancer and their relatives.[28] Research done on these initiatives exclusively providing care to patients with advanced cancer and their relatives is rare. Yet, two reviews focused on the combination of formal and informal care in general palliative care.[29 30] Both reviews stated that these initiatives are of added value in providing information and support for patients and relatives.

Such initiatives could thus potentially be a way to meet the expected increase in non-medical care needs of patients with advanced cancer and their relatives in the future. This expected increase in unmet needs is due to both successful extension of the oncology patients' lives, as well as the increase in new cancer diagnoses as a result of an ageing population and lifestyle changes.[31] Providing non-medical formal and informal services to patients with cancer and their relatives can help meeting their unmet needs in a cost-effective way as the services promote the patients' and relatives' self-reliance and autonomy, leading to potential savings of costly formal care.

To gain understanding into whether indeed the services of such initiatives may be able to meet those unmet needs, more insight into the patients' and relatives' specific care needs is indicated. Thus, this study aimed to gain insights into specific disease and care-related problems and needs of patients with advanced cancer and their relatives and its association with the patients' and relatives' sociodemographic characteristics. This was done from a perspective not yet introduced in literature, namely that of the types of support that can be provided by centres for information and support.

METHODS

Study design

This study used baseline data from the eQuiPe study.[32] The eQuiPe study is a prospective observational cohort study focusing on the perceived quality of care (QoC) and QoL of patients with advanced cancer and their relatives. Patients and relatives reported their QoL and QoC by questionnaires and their responses were linked to the clinical data from the Dutch Cancer Registry. More information regarding the recruitment and the study procedure is reported elsewhere.[32]

Setting and recruitment

Patients with advanced cancer and their relatives were approached to participate by healthcare professionals from the hospitals' departments of medical oncology, pulmonology and urology of 40 hospitals in the Netherlands. Recruitment took place between November 2017 and January 2020.

Study population

All patients (>18 years) with a diagnosis of a solid metastasised tumour (stage IV) were eligible for inclusion. There were additional criteria defined for patients diagnosed with breast cancer or prostate cancer.[32] Relatives of the included patients, as indicated by the patients, were also invited to participate in the study. Patients or relatives could participate in the study irrespective of the participation of the other. Patients were also allowed to invite more than one relative to participate in the study.

Outcome measures

Socioeconomic demographics

Baseline data of the patients' age, gender, marital status, educational level and nationality were used. The relatives' baseline data consisted of information on age, gender, marital status, educational level, nationality and the nature of the relationship with the patient.

Marital status was grouped into 'partner' (answers: 'in a relationship/living together' and 'in a relationship/living apart') and 'no partner' (answers: 'widow/widower' and 'Single'). The patients' and relatives' educational level was grouped into 'low' (answers: 'primary education' and 'secondary education'), 'medium' (answer: 'vocational education or advanced general education') and 'high' (answer: 'university (bachelor's or master's degree, PhD))'. Lastly, the relatives' demographic 'nature of relationship' consisted of the categories 'spouse', 'son or daughter', 'other family member' and 'friend', the category 'other' was excluded due to heterogeneity of the relatives' answers.

Problems and needs assessments

Healthcare problems and needs were measured with the short version of the validated Problems and Needs in Palliative Care questionnaire (PNPC-sv).[33] The PNPC-sv consisted of either a patient form or a relative form to measure palliative care problems and needs. The PNPC-sv is a self-report questionnaire that consists of 33 items for patients and 34 items for relatives. Each item consists of two questions, namely if patients or relatives experience a problem (yes/somewhat/no) and whether they want professional attention for that specific item (yes, more/as much as now/no).

Table 1 Number of PNPC-sv items per domain—patient and relative form

No of items	Patients	Relatives
Total	40	44
Physical symptoms	12	2
(Functional) autonomy	4	4
Social issues	6	3
Psychological issues	7	8
Spiritual issues	4	3
Financial problems	2	2
Need of information	5	5
Daily activities		1
Caregiving		5
Relationship with the patient		3
General matters in providing assistance		5
Other matters		3

PNPC-sv, Problems and Needs in Palliative Care questionnaire.

PNPC-sv patient form

The original PNPC-sv patient form consists of the following domains: daily activities, physical symptoms, autonomy, social issues, psychological issues, spiritual issues, financial problems and need of information. The eQuiPe study group conducted a qualitative study to gather input from patients with advanced cancer and their relatives in the development of the questionnaires used.[34] Consequently, the study group added four items on 'need of information', two items on 'psychological issues', three items on 'physical symptoms' and one item on 'social issues' compared with the original patient form.[8] All three original items regarding daily activities were removed due to duplication and the questionnaire used in this study consequently contained 40 items (online supplemental table 1). An overview of the number of items per domain is provided in table 1.

PNPC-sv relative form

The original PNPC-sv relative form contains the following domains: caregiving, physical symptoms, relationship with the patient, functional autonomy, social issues, psychological issues, spiritual issues, financial problems, daily activities, general matters in providing assistance, need of information and other matters. The form for relatives used in this study consisted of 44 item: based on the above-mentioned qualitative study,[34] the eQuiPe study group added 1 extra item on 'social issues', 4 on 'psychological issues', 4 items on 'need of information' and one item on 'general matters in providing assistance' (online supplemental table 2). An overview of the number of items per domain is provided in table 1.

Sum scores problems and unmet needs and scores per domain

A 'problem' was defined when patients and relatives answered 'yes' or 'somewhat' when asked whether a specific item was considered a problem. Each item defined as a problem got a value of 1, otherwise, the item got a value of 0. These values were used to calculate a sum score over all items together, with higher scores meaning that patients and relatives experienced more problems. The same was done for the experienced unmet needs: an item was defined as an unmet need if patients and relatives answered 'yes, more' when asked whether they wanted more professional attention for a specific item. Each item defined as an unmet need got a value of 1, otherwise, the item got a value of 0. Sum scores were also calculated for each domain separately.

Because the patient form and relative form, and the corresponding domains, consisted of unequal numbers of items, the sum score and the scores per domain were normalised by a division by the maximum possible score of that domain, and multiplied by 100. This produced a scale of 0 meaning no problems/needs, and 100 meaning all problems/needs (within a domain). Missing values up to a maximum of half the number of items of the domain were imputed using the mean of the available items.

Statistics

All statistical analyses were performed using the Statistical Package for the Social Sciences V.28 (SPSS; http://www.spss.com). Descriptive statistics were used for frequencies, means, medians and ranges of the study variables. The distribution of the patients' and relatives' normalised unmet needs sum scores and the scores per domain were assessed using histograms and the Kolmogorov-Smirnov test. Due to the non-normal distribution of all normalised scores, non-parametric tests were used. The Spearman's rank correlation and the Kruskal-Wallis H test were used to test whether there were factors associated with the experienced unmet needs. A two-sided significance level of $p<0.05$ was considered statistically significant for all tests and, if appropriate, effect sizes were reported based on the used tests. The size of the effects was based on r and a value of 0.10 is considered a small effect, 0.30 a medium effect and 0.50 a large effect.[35] Correlation coefficients above 0.30 were considered clinically relevant.[36]

RESULTS

Patients' and relatives' characteristics

A total of 1103 patients with advanced cancer and 831 relatives were included. Details of the inclusion process are published elsewhere.[37] The patients' median age was 67 years (range 29–93), the relatives' median age was 63 years (range 18–87). Around half of the patients (49%) and the majority of relatives (61%) identified as female. Most patients (82%) and relatives (95%) were in a partner relationship and the involved relatives were most often the patients' spouses (74%). The majority of all participants had a Dutch nationality. Table 2 provides an overview of the patients' and relatives' characteristics.

Table 2 Characteristics of patients with advanced cancer (n=1103) and their relatives (n=831)

	Patients	Relatives
	n (valid %)	n (valid %)
Gender		
Female	541 (49.0)	507 (61.0)
Male	562 (51.0)	324 (39.0)
Marital status		
Partner	909 (82.6)	790 (95.2)
No partner	192 (17.4)	40 (4.8)
Missing	2	1
Education level		
Low	328 (30.0)	17 (2.1)
Medium	450 (41.2)	564 (68.4)
High	314 (28.8)	243 (29.5)
Missing	11	7
Self-reported nationality		
Dutch	1001 (96.6)	812 (98.2)
Not Dutch	35 (3.4)	15 (1.8)
Missing	67	4
Nature of relationship		
Spouse		612 (74.3)
Son or daughter		140 (17.0)
Other family member		42 (5.1)
Friend		26 (3.2)
Other		4 (0.5)
Missing		7

Experienced problems and unmet needs

On average, patients experienced 41.9 problems (SD=19.9) and the average number of problems for which patients wanted additional attention was 9.6 (SD=14.6). More than half (55.2%) of all patients reported at least one unmet care need. Relatives experienced 35.4 problems on average (SD=21.0) and the average number of problems for which relatives wanted additional attention was 12.0 (SD=16.4). In addition, more than half (60.8%) of all relatives reported at least one unmet care need.

Patients' experienced problems and unmet needs

Patients experienced, on average, most problems in the domains of autonomy (M=61.7, SD=37.8) and psychological issues (M=60.3, SD=29.0) (see figure 1). On item-level, patients reported the problem 'fatigue' most frequently (83.2%), followed by 'worrying about the future of my loved ones' (80.8%), 'difficulty coping with the unpredictability of the future' (76.8%) and 'fear of metastases' (76.8%) (see online supplemental table 1).

Patients experienced, on average, most unmet care needs in the domain of psychological issues (M=14.0, SD=24.2), followed by the domains of financial

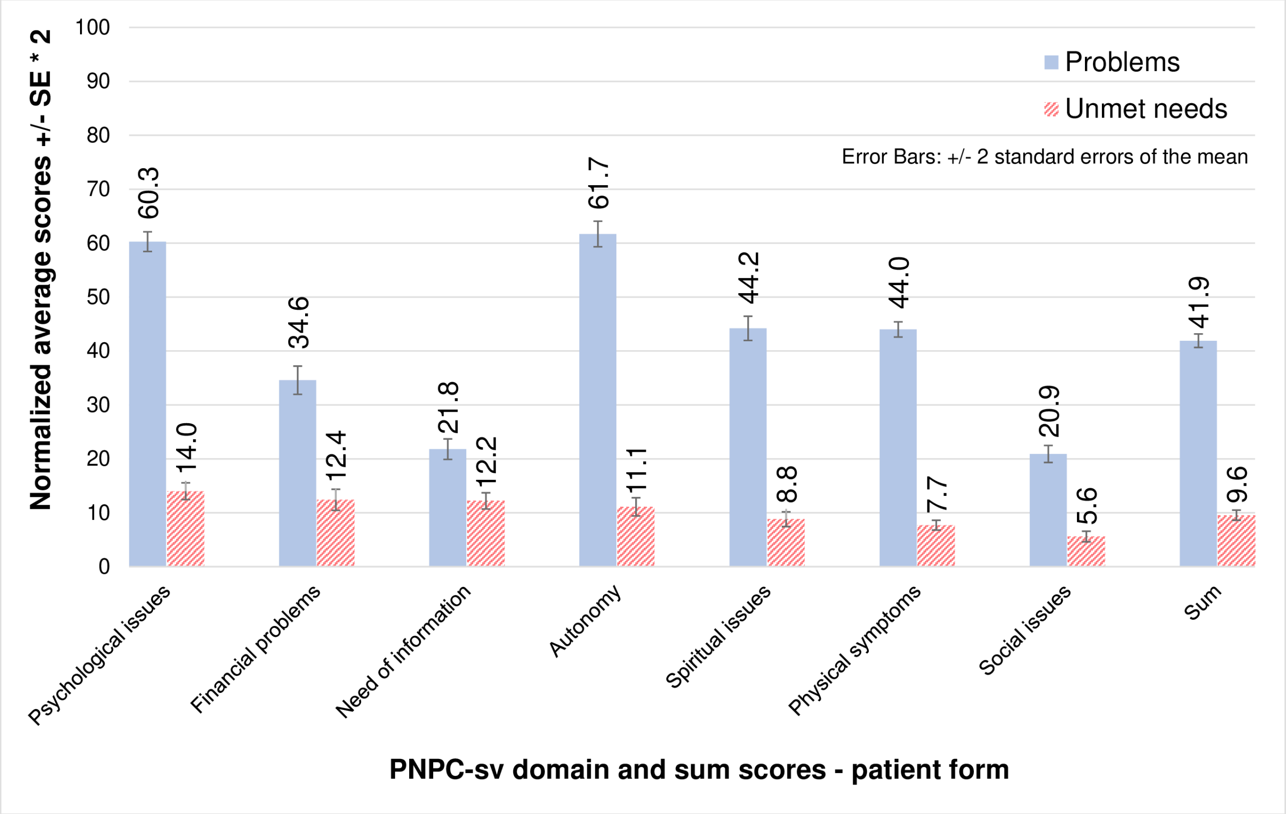

Figure 1 The patients' normalized average scores of experienced problems and unmet needs per domain of the PNPC-sv patient form (Scale: 0 – 100). PNPC-sv, Problems and Needs in Palliative Care questionnaire.

problems (M=12.4, SD=30.3) and informational needs (M=12.2, SD=24.0) (see figure 1). On item level, the problem 'worrying about the future of my loved ones' was most frequently considered as an unmet need (22.0%), followed by 'fear of metastases' (20.6%)' and 'difficulty coping with the unpredictability of the future' (17.8%). A broad range of topics within multiple domains was considered as unmet needs. A list of all items, ranked by the percentages of all patients for whom the item was considered an unmet need is presented in online supplemental table 1.

Relatives' experienced problems and unmet needs

Relatives experienced, on average, most problems in the domains about psychological issues (M=59.2, SD=26.6) and spiritual issues (M=53.6, SD=39.5) (see figure 2). On item level, the problem mentioned most frequently was 'fear for physical suffering of the patient' (88.3%), followed by 'fear of metastases' (83.9%), 'fear of an unpredictable future' (79.3%) and 'fear of death' (69.6%) (see online supplemental table 2).

Similar to patients, relatives, on average, specifically experienced unmet needs in the psychological issues domain (M=17.7, SD=25.7). In addition, relatives also experienced unmet needs in the domain of caregiving (M=16.2, SD=25.0) (see figure 2). On item level, the item mentioned most frequently was 'fear for physical suffering of the patient' (32.8%), followed by 'fear of metastases' (29.3%) and 'knowing what physical signs I should notice' (27.5%). A list of all items, ranked by the percentages of all relatives for whom the item was considered an unmet need, is presented in online supplemental table 2.

Factors associated with unmet needs

Factors associated with the patients' unmet needs

Multiple statistically significant correlations were found between the normalised sum score and various domain scores and the patients' age, gender, marital status, educational level and nationality, using the Spearman's rank test (online supplemental table 3). Multivariate analyses were not performed as no factors above the clinically relevant threshold were found in the univariate analyses ($r_s \leq 0.142$).

Factors associated with relatives' unmet needs

Similar to patients, non-parametric correlation tests showed multiple statistically significant correlations between the normalised sum score and various domain scores and the relatives' age, marital status, educational level and nationality. None of the correlations coefficients were found to be higher than 0.30 ($r_s \leq 0.158$) (online supplemental table 4A).

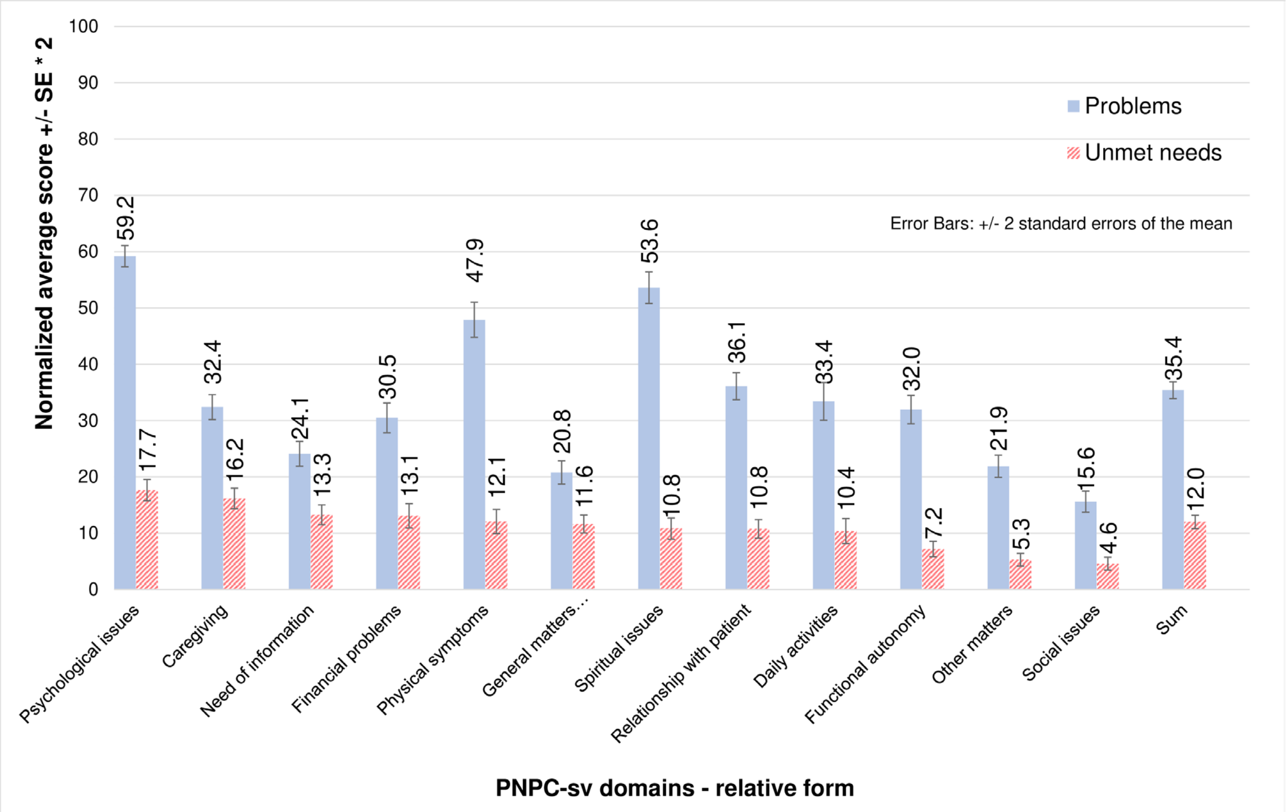

Figure 2
The relatives' normalized average scores of experienced problems and unmet needs per domain of the PNPC-sv patient form (Scale: 0 – 100). PNPC-sv, Problems and Needs in Palliative Care questionnaire.

Significant effects of the factor 'nature of the relationship' were found on the sum scores, and the domain scores for 'caregiving', 'general matters in providing assistance', 'relationship with the patient' and 'physical symptoms', using the Kruskal-Wallis H test. Pairwise comparisons, using the Bonferroni correction, were used to compare the differences between categories and found that the patients' children generally showed more unmet needs than relatives of different categories on the unmet needs total score, and on the domains 'caregiving', and 'general matters in providing assistance'. None of the effect sizes were greater than r=0.218 (online supplemental table 4B) and thus multivariate analyses were not performed.

DISCUSSION

This study aimed to gain insights into the disease and care-related problems and care needs of patients with advanced cancer and their relatives. Moreover, this study wanted to explore whether there are socioeconomic demographics associated with these experienced unmet care needs. This was done from the perspective of the types of support that can be provided by centres for information and support.

Previous research, including recent reviews by Hart *et al*[15] and Wang *et al*,[14] only focused on the patients' and relatives' experienced unmet care needs. In addition to these unmet needs, our study aimed to gain insights into the problems perceived by patients and their relatives. Patients and relatives experienced most problems for psychological issues and some of the items within this domain were experienced a problem by (more than) four out of five patients and relatives. Patients also experienced comparable large problems in the autonomy domain, whereas relatives experienced considerable problems in the spiritual domain. Notably, the wish to address these problems was considerably lower. On item level, the most often experienced unmet need was mentioned by almost one out of every four patients and by one out of every three relatives. This finding is relevant as the services of the centres for information and support should be organised following the needs of potential visitors, and not necessarily their problems.

In this study, both patients and relatives wanted relatively the most attention for psychological issues, but after that, the reported unmet needs were almost evenly distributed over all domains. The wide range of the patients' and relatives' unmet needs identified in this study was also reported in a recently published scoping review by Hart *et al*,[15] which showed that patients experienced the highest unmet needs in 'financial', 'health system and information', 'psychological' and 'physical and daily living' domains, whereas caregivers reported the highest unmet needs in the domains of psychological issues and the domain of 'patient care and support', including illness, treatment and care-related information.

Notably, the review by Hart *et al* reported the most unmet needs of patients in the financial domain. However, this domain did not stand out from the other domains in our study. This inconsistency could be related to differences in the healthcare reimbursement systems. Dutch patients are insured and receive reimbursement for the care they receive through their insurance, whereas patients in some other countries have to pay for their treatment themselves. This explanation is supported by the fact that none of the Dutch articles included in the review by Hart *et al*, reported the most unmet needs in the financial domain.

We additionally gained insight into the specific unmet needs of patients and their relatives, by investigating our data on item level. On item level, we found that the unmet needs of both patients and relatives mainly consisted of fears and worries, followed by a broad range of topics they wanted to get information on. Our findings suggest that the centres for information and support should provide informational and supportive care on a broad range of topics in order to meet the needs of (potential) visitors. Further, it is worth noting that the item most often experienced as an unmet need by patients was 'worrying about their beloved one', whereas the item most often experienced as an unmet need by relatives was 'fear for the physical suffering of the patients'. Hence, it is important to bear in mind that patients and relatives face the disease's trajectory and its consequences together.

Centres for information and support can play a role in reducing the unmet needs of patients with advanced cancer and their relatives as these centres focus on both patients and relatives, offer a wide range of services, and are not restricted to a limited amount of time. The centres combine the beneficial effects of the multiple types of informal care provided, together with the closeness to formal care[28]: the support provided by trained volunteers helps patients with cancer and their relatives to reduce cancer-related distress, encourage self-management, and seek professional support if needed.[25 38] Furthermore, these centres arrange peer meetings and beneficial effects of peer support in terms of coping, cancer-related knowledge and self-efficacy, have been described in reviews that focused on patients with cancer.[26 39 40] Moreover, various group workshops, individual treatments and information sessions on diverse subjects help to address the supportive and informational needs of patients and their relatives.[28] Lastly, these centres can play a role in targeted referrals to professional medical care as they collaborate with formal care.

The statistically significant effects of the patients' and relatives' multiple socioeconomic demographics on the experienced unmet needs were considered small. These minimal effects found in this study, and the inconsistent findings of systematic reviews that focused on associations between socioeconomic demographics and the unmet care needs of patients with advanced cancer and their informal caregivers,[14 15] emphasise that there is no 'one-size-fits-all' type of care. Thus, the care provided by these centres should be tailored to the personal needs of patients and relatives.

It should be noted that these centres are not meant to be compulsory for patients and relatives and also our results show there is no reason to believe that all patients with advanced cancer and relatives are in need of the care offered by these centres. Yet, these centres can be of added value in reducing their unmet needs as these centres can tailor the care provided to the personal needs of its visitors.

Limitations

The data used in this study solely consisted of baseline measurements of patients with advanced cancer and their relatives. It is known that the needs of patients with advanced cancer change over time and longitudinal data are needed to get further insight into the specific unmet needs of these patients and their relatives at the end of life.

Furthermore, the distribution of socioeconomic demographics reveals that this study is not fully representative for all patients with advanced cancer and their relatives living in the Netherlands. In this study, participants were more educated than average, had a partner and only a small number of non-Dutch patients and relatives participated. This information could imply that mainly patients with a high socioeconomic status participated.

CONCLUSIONS

This study showed that the unmet care needs of patients with advanced cancer and relatives in the Netherlands most often consisted of psychological issues, mainly fears and worries, followed by a broad range of topics within multiple domains of life. The findings show that the unmet needs are not restricted to items related to medical care. This supports the idea that centres for information and support can play a role in reducing the unmet care needs of patients with advanced cancer and their relatives.

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Competing interests None declared.

Patient consent for publication Written informed consent is obtained from all study participants. This article does not contain any studies animal subjects performed by any of the authors.

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