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research article

Unmet needs for information and support of cancer patients and carers: a structured questionnaire study

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We examine the unmet needs for information and support of cancer patients and carers. A questionnaire study was performed among patients (n = 135) and carers (n = 73) at Kuopio University Hospital, Finland. Data are analysed using SPSS 27 by t-test, cross-tabulation and cluster and variance analyses. Patients and carers received less support than information. Older and less-educated individuals and males had more unmet needs. Carers received less information and support than patients. Carers expressed unmet needs particularly when they had limited opportunities to discuss with healthcare professionals. Individual needs of patients and carers should be addressed throughout the cancer care pathway.

Keywords cancer • carer support • quality of care

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Introduction

Timely information and various forms of support are important in different phases of the cancer trajectory (Zebrack et al, 2007; Newby et al, 2015), both

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for patients and for their carers. The role of cancer patient carers is often difficult (Teixeira and Pereira, 2013): anxiety (Stafford and Judd, 2010), the stress of carrying the emotional burden of cancer patients and feelings of abandonment are not uncommon (Price et al, 2022), and carers may even need more psychosocial support and information about the disease than the patients themselves (Gustavsson-Lilius, 2010; Niemelä et al, 2010).

The carer often functions as the patient's most important source of support (Gustavsson-Lilius, 2010; Teixeira and Pereira, 2013). The cancer trajectory may be very long for both the patient and the carer and may consist of different phases, from diagnosis to treatment, as well as cancer recurrence and palliative care. There are unmet needs among family carers related to the duration of caregiving, the patient's physical condition and performance, the age of the carer (Zavagli et al, 2022), and poor communication when the carer wrestles with multiple concerns (Johnson et al, 2021). Significant barriers to carer identification exist, including carer self-identification issues and definitional issues around the label 'carer' (White et al, 2019). This presents an additional impediment to our understanding of the need for support of cancer patient carers.

Carers benefit from peer support (Landry-Dattée et al, 2016), from relaxation exercises (Stafford and Judd, 2010), from targeted, timely and valid communication (Li et al, 2020), and from information on patient care (Berry et al, 2016). The education of caregivers, the training of their skills and therapeutic counselling favourably affect how carers perceive their burden, quality of life, coping skills and knowledge and alleviate depression and distress (Berry et al, 2016). Furthermore, patients who are effectively supported by a carer are less symptomatic and experience better physical and mental health (Brazil et al, 2014). The high-priority needs of carers include understanding the patient's illness and symptoms, how to provide personal care (Laabar et al, 2022; Price et al, 2022), and how to access healthcare and schedule healthcare appointments (Gunn et al, 2022). Unfortunately, these reasonable needs of support experienced by carers are often overlooked, as it is the patient – not the carer – who is the client of the healthcare system.

This questionnaire study is part of a larger project evaluating the support needs of cancer patients and their carers. In this study, 'carers' refer to spouses, family members, other relatives, close friends and informal carers who identify themselves as carers for a person with cancer. We have previously published a qualitative study where we examined the kinds of support that cancer patients and their carers need and ways to organise this support (Tiirola et al, 2021). That study collected data from professionals who were members of the Cancer Society of Finland, which gave us insight into the non-governmental healthcare organisation's views on care pathways. We found that both patients and their carers need more information, more psychosocial support and more financial counselling, particularly after diagnosis, at cancer relapse and when the patient receives palliative care. These results have been used to identify the focus of this study.

The key aim of this study is to clarify what kind of information and support patients and carers receive and to identify what additional support and information they need. An additional aim is to compare the quantitative information and support needs of patients and carers and to elucidate the factors that identify the patients and carers in the greatest need of support. This will facilitate the further development of our support services and appropriately direct our limited resources. Results emerging from this study also lead us to investigate the impact of well-being in relation to the sufficiency of information and support for patients and carers.

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Methods

Data collection and items analysed

The participants were cancer patients and their carers. They were enrolled in three different outpatient oncological departments and two inpatient oncological wards at Kuopio University Hospital, Finland, between December 2017 and February 2018. The carers self-identified themselves as such, and there were no other specific qualifications they needed to fulfil. Invitations to participate and the study questionnaires were placed in the waiting rooms of outpatient departments and wards, along with boxes for returning the completed questionnaires. Nurses and doctors also invited patients and their carers to participate.

The questionnaires were largely similar for patients and carers, only slight modifications were made, for example: for patients, 'How much of the following forms of support have you received during your illness?'; and for carers, 'How much of the following forms of support have you received during the illness of your beloved one?'. Responses followed a Likert scale from 1 to 5 (1 = very little; 2 = a little; 3 = not a little and not much; 4 = much; and 5 = very much) to measure the information and support received and needed. The questions were formulated based on previous studies of information and support received and needed during different stages of cancer (Girgis et al, 2011; Teixeira and Pereira, 2013; Turner et al, 2013), as well as our earlier findings (Tiirola et al, 2021). Several healthcare professionals (some of whom identified themselves as patients or carers) reviewed the questionnaire, including physicians, nurses, psychotherapists, a social worker and a physiotherapist.

The questionnaires included three sections: (1) demographic and other baseline data (ten variables, with six analysed for this article; the four remaining questions concerned parity, whether the participant had children, what kind of treatment they had received and in which geographic area they were being treated/followed up); (2) information and support received and needed (six variables on information received, six on support received, six on information needed and six on support needed; the sixth variable in each section was an open-ended question, 'other, please specify', which were not included in the sum variables because there were only a few responses); (3) and questions addressing the need for the development of services (13 variables, which are not reported here). The participants were also asked whether they considered that the treatment they had received had been good. We did not ask participants about their emotional distress, but we did address their general well-being with the broad question: 'How is your general well-being?'. A translation of the questions is provided as an Online Appendix.[1]

The concept of 'support' is broad and includes, for example, psychosocial support, crisis support, rehabilitation and adaptation training, discussions with healthcare professionals, peer support, and even financial support. When all these items are included, the overarching term 'support' is used; otherwise, the form of support is defined in the text. We used the same classification for patients and carers.

Statistical analysis

The data were analysed with the SPSS 27 software, using descriptive and explanatory statistical parametric and non-parametric methods. Frequencies, means and variances

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were used to describe the data. The independent samples *t*-tests, cross-tabulation, cluster analysis and analysis of variance were used for the analysis of statistical significance (Tabachnick and Fidell, 2019) (for details, see later).

Formation and analysis of sum variables

The support received and needed was analysed by principal axis factoring (Varimax rotation). Since the items correlated with each other, factor analysis was used to statistically justify that each individual variable could be transformed in the scales containing all items under the same question category. Based on the eigenvalue criterion ($\lambda > 1$), most variance in each question group could be expressed by only one factor. In percentage terms, the first factors explained most (58 to 68 per cent) of the total variance of each group, and all four sets of questions could be interpreted as one-dimensional and hence used for the formation of sum variables. The purpose of the factor analysis was to check the dimensionality of the used variable groups.

As detailed in the Online Appendix, the following four scales (= sum variables) were used to measure received and needed support: (1) received information (Q2 questions); (2) received support (Q3 questions); (3) needed information (Q8 questions); and (4) needed support (Q7 questions). The scales examined by factor analysis were interpreted as comprehensive indicators of the information and support received and needed. To allow comparisons, the scales were standardised into *Z*-variables (mean = 0; standard deviation = 1). An independent samples test was used for statistical analyses. Cohen's *d* and Pearson's *r* are also presented.

The reliability of each scale, measured with Cronbach's alpha, was as follows: received information = 0.87; received support = 0.80; and needed information = 0.86. These assessments indicate high reliability.

Cluster analysis

K-means clustering (with Euclidean distance) was applied to identify those patients and their carers who would need the most support. For this purpose, variables measuring how sufficient the information and support had been included in the clustering. This was evaluated by Questions 6.1, 6.2, 6.4 and 6.5 (see the Online Appendix). Fisher's linear discriminant analysis was used to find out which of the clustering variables best separate the clusters from each other in the group of both patients and carers.

Several clusters were tested during the analysis. The final and best model included two clusters for patients and two for carers. The patients and carers in the first cluster (n = 81 patients and 41 carers) received more information and support than those in the second cluster (n = 47 patients and 28 carers). For both patients and carers, all means of single variables in the first cluster exceeded the corresponding values in the second cluster, and these differences are statistically significant.

Other statistical methods

The relationship between demographic and other background variables and information and support needs was analysed using cross-tabulation. In addition, a *t*-test (for gender), Spearman's correlation (for age) and one-way analysis of variance (for other demographic variables) were used. The type of cancer could not be included in

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these analyses, as the number of participants with each type of cancer was too small for this. Multivariate regression analysis was not feasible because of the small sample size.

Missing data analysis

The main cause of non-response was poor health or a lack of a convenient moment to fill out the questionnaire. The motivation and possibilities of healthcare staff to inform about questionnaires varied mainly due to the other tasks of the staff. Missing data analysis was performed manually and showed that data were missing 'at random' and there was no systematic lack of data for any of the questions. The amount of missing data was small: on average, only 10 per cent of the items were not answered by the participants.

Ethics

The study received a positive opinion from the Research Ethics Advisory Board of the University of Eastern Finland in 2017 (No. 18/2017). The study followed good scientific practices related to data preservation and security. Non-participation did not influence patient treatment (Fouka and Mantzorou, 2011).

Results

In total, 135 cancer patients and 73 carers responded to the questionnaire. The characteristics of participants are presented in Table 1. The participating patients were born between 1928 and 2000, and the carers were born between 1937 and 1992. Patients have been treated in the catchment area of the hospital district of Kuopio University Hospital. The mean age of the patients was 63 years and of the carers was 65 years. The median age of both groups was 66 years. Of the 73 carer participants, 69 were in a relationship and adults, so it is likely that most of the carers were spouses.

Descriptive results

The distributions of different forms of information and support received and needed by patients and carers are presented in Figures 1 and 2. In this article, the categories 'carried out well' or 'carried out poorly' concerning support or information refer to the respondents' subjective judgement on the quantity and quality of information or support, while the term 'unmet need' refers to situations where the participants stated that they needed more information and/or support.

Information received and needed

Patients and their carers received varying amounts of information about cancer and related topics, with carers receiving substantially less than patients (see Figure 1). For several of the items in Figure 1, approximately 30 per cent of the participants reported that they received little or very little information, and another 30 per cent received much or very much. Receiving information about the cancer disease, treatment and

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Table 1: Baseline characteristics of patients and carers

Characteristics	Patients Number (%)	Carers Number (%)
Sex		
Female	84 (63%)	52 (71%)
Male	50 (37%)	21 (29%)
Age (years)		
≤ 50	19 (16%)	6 (9%)
51–65	40 (34%)	27 (40%)
≥ 66	60 (50%)	34 (51%)
Education		
Higher education[a]	33 (25%)	15 (22%)
Secondary education	48 (36%)	26 (37%)
Primary education	41 (31%)	16 (23%)
Year of the patient's cancer diagnosis		
2017 (less than one year since diagnosis)	60 (50%)	34 (49%)
2016–15 (1–3 years since diagnosis)	27 (23%)	16 (23%)
Before 2015 (more than 3 years since diagnosis)	33 (28%)	20 (29%)
Cancer type		
Breast cancer	46 (34%)	12 (17%)
Haematological malignancy	30 (22%)	17 (24%)
Gastrointestinal cancer	13 (10%)	6 (8%)
Prostate cancer	12 (9%)	10 (14%)
Other cancer (not specified)	31 (23%)	25 (36%)
Unknown	2 (2%)	1 (1%)
Stage of disease		
Localised, being treated	57 (43%)	28 (39%)
Asymptomatic, being followed up	27 (20%)	15 (21%)
Recurrent or metastatic	41 (31%)	26 (36%)
Unknown	8 (6%)	4 (5%)

Note: [a] University education (at least a bachelor's degree).

follow-up was considered to have been carried out well in both groups: 84 per cent of patients and 68 per cent of carers reported that they had received much or very much information.

On the other hand, 43 per cent of carers and 35 per cent of patients considered that they had received little or very little information about rehabilitation and adaptation training. Furthermore, 43 per cent of carers and 29 per cent of patients reported that they had received little or very little information about how to talk about cancer with persons they were close to, and 40 per cent of carers and 39 per cent of patients reported that they had received little or very little information about financial support and benefits.

Almost 80 per cent of carers but only about 40 per cent of patients reported that they still needed much or very much more information about the disease, treatment and follow-up. More than half of the carers and about a quarter of the patients needed

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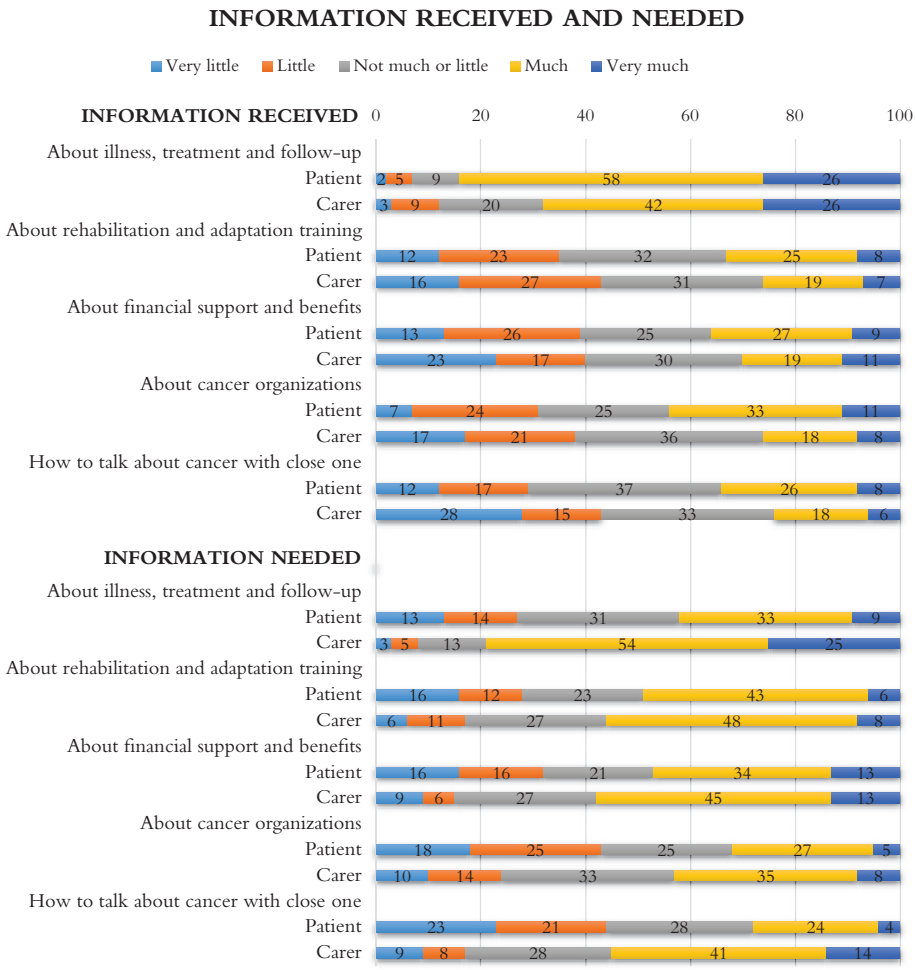
Figure 1: Information about different cancer-related topics received and needed by patients and by carers



Note: Numbers refer to percentages.

much or very much more information on how to speak about cancer with persons they were close to (that is, the patient with the carer and the carer with the patient). Over half of carers also reported that they needed much or very much more information about financial benefits, patient rights, rehabilitation and adaptation training, and the situation was almost the same for patients (see Figure 1).

Support received and needed

The receipt of different forms of support was in general very limited (see Figure 2). Over 50 per cent of all participants, both patients and carers, reported that they had received very little support in general. The only exceptions to this were discussions with healthcare professionals, which patients had benefited more from than other forms of support. Still, 23 per cent of the patients reported that they had had very

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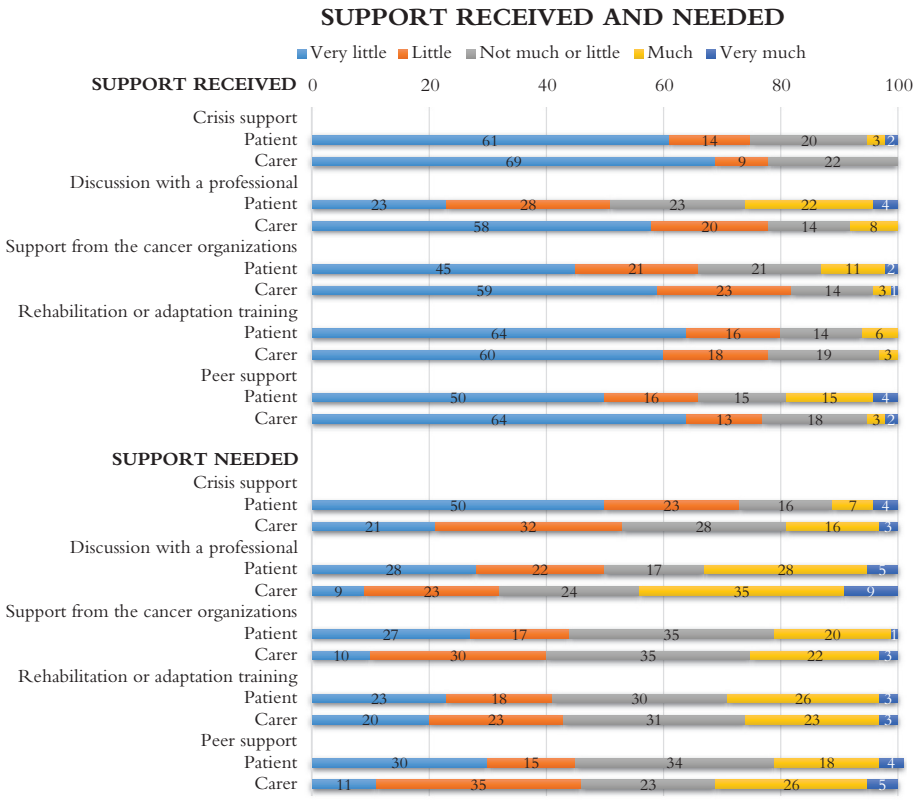
Figure 2: Support for different cancer-related items received and needed by patients and by their carers



Note: Numbers refer to percentages.

few opportunities for discussions with healthcare workers.The carers pointed out that they had received very little peer support (64 per cent) and too few opportunities for discussions with healthcare professionals (68 per cent).

In general, carers reported more unmet needs for different forms of support than patients. This was especially true for opportunities for discussion with healthcare professionals: 44 per cent of carers but only 33 per cent of patients reported that they needed more or very many more opportunities for discussions with healthcare professionals. Only 11 per cent of the patients reported that they needed crisis support much or very much; the corresponding figure for the carers was 19 per cent.

Table 2 presents the statistically significant differences in received and needed information and support items between patients and carers. Carers reported that they had significantly fewer opportunities than they needed to discuss their thoughts and feelings about cancer with healthcare professionals ($p < 0.001$) and that they needed more information about how to talk about cancer ($p < 0.001$). Carers also needed significantly more information about the disease, treatment and follow-up ($p < 0.001$); this was the greatest unmet need as measured by the mean Likert score. Carers also expressed a need for crisis support significantly more often than patients ($p = 0.001$). The patients expressed a lower unmet need for crisis support than for

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Table 2: Significant differences in information and support received and needed among patients and carers

Received and needed support	Group	Mean	SD	Cohen's *d*	Pearson`s *r*	*p*-value*
Received information about support provided by cancer organisations	Patients	3.16	1.13			
	Carers	2.78	1.16	.33	.16	0.033
Received information about how to talk about cancer with the next of kin	Patients	3.02	1.12			
	Carers	2.61	1.24	.36	.17	0.023
Received support in the form of opportunities to discuss thoughts and feelings with a professional	Patients	2.55	1.19			
	Carers	1.72	0.98	.74	.33	< 0.001
Received support from cancer organisations	Patients	2.03	1.13			
	Carers	1.66	0.94	.35	.17	0.025
Received peer support (from groups or individuals)	Patients	2.07	1.28			
	Carers	1.66	1.00	.35	.17	0.019
Needed more information about the disease, treatment and follow-up	Patients	3.11	1.16			
	Carers	3.94	0.93	–.77	–.35	< 0.001
Needed more information about the support provided by cancer organisations	Patients	2.76	1.18			
	Carers	3.17	1.09	–.36	–.17	0.019
Needed more information about how to talk about cancer with the next of kin	Patients	2.65	1.20			
	Carers	3.42	1.10	–.66	–.30	< 0.001
Needed more crisis support	Patients	1.91	1.15			
	Carers	2.49	1.09	–.51	–.24	0.001
Needed more opportunities to discuss thoughts and feelings about cancer with a professional	Patients	2.59	1.29			
	Carers	3.10	1.16	–.41	–.19	0.009

Note: * Significance level p < 0.05, analysed by independent samples test.

other forms of support. Patients and carers both reported that the information they received about financial benefits and patient rights was poor (average Likert score of 2.6 for patients and 2.4 for carers).

Care experience was assessed by the statement: 'I have' or 'The person I am close to has received good treatment/care (Q6.3)'. The replies were very favourable (average Likert score of 4.6) for both groups. Since this item was not directly related to information and support received, it was not included in the analysis of sum variables.

Analysis of sum variables

Sum variables were calculated to summarise data (see Table 3), including sum variables that measure information (five variables) and support (five variables) received, as well as information (five variables) and support (five variables) needed (for details, see the 'Methods' section). All sum variables were systematically and statistically different between patients and carers. Carers received significantly less information and support than patients and had greater unmet needs for information and support. The biggest difference between the groups was the need for information ($p < 0.001$).

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Table 3: Sum variables for information and support received and needed by patients and carers

Sum variable	Group	*n*a	Average sum variable	*p*-value*
Received information	Patients	112	16.1	
	Carers	65	14.4	0.017
Received support	Patients	105	9.8	
	Carers	60	8.2	0.009
Needed information	Patients	115	14.7	
	Carers	57	17.5	< 0.001
Needed support	Patients	105	12.1	
	Carers	60	13.8	0.023

Notes: [a] Number of subjects with the corresponding value. * Significance level $p < 0.05$, analysed by *t*-test.

Cluster analysis

Two distinct clusters for patients and carers were identified for cluster analysis. Cluster 1 contained patients and carers who considered that they had received enough information and support and that they had had sufficient opportunities for discussions with healthcare professionals. Cluster 2 contained the patients and carers who reported that they had not received enough information and support.

When different baseline variables of the patients were examined, a factor that differentiated the two clusters was patient well-being. We did not ask the participants about emotional distress, but we examined general well-being with the broad question: 'How is your general well-being?'.

Patients in Cluster 1 reported significantly better well-being (average Likert score of 3.67) than those in Cluster 2 (average Likert score of 3.19) ($p = 0.003$, cross-tabulation). In discriminant analysis, the best variable separating the two clusters was whether the carer had had sufficient opportunities for discussions with healthcare professionals. The loading for this factor in the discriminant function was very high (at 0.78).

Among the carers, the differences between the two clusters were even larger than among the patients. There were also significantly more men in Cluster 2 ($p = 0.009$, cross-tabulation). In contrast to the patients, the general well-being of the carers did not differ between the clusters. A discriminant analysis showed that the primary variable differentiating these two clusters was whether the participant, that is, the carer, had had sufficient opportunities for discussions with healthcare professionals. The loading for this factor in the discriminant function was high (at 0.64).

Support needs in relation to background information

To identify those who need more support and information, we evaluated the unmet needs in relation to the background information of the participants (see Table 4). Among carers, women were more likely to report that they had received more information and had had more opportunities for discussion with

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Table 4: Information and support needs of patients and carers by baseline characteristics

Characteristics	Patients	Carers	Conclusions
Sex[a]	Women (compared to men): • received more peer support (L = 2.26 versus L = 1.75; p = 0.004); and • expressed a need for more information about cancer organisations' services (L = 2.96 versus L = 2.32; p = 0.004).	Women (compared to men) received: • more information about the disease, treatment and follow-up (L = 3.96 versus L = 3.33; p = 0.02); • more information about economic benefits and patient rights (L = 2.90 versus L = 2.26; p = 0.04); • enough verbal information (L = 2.74 versus L = 3.0; p = 0.03); • enough written information (L = 3.67 versus L = 2.89; p = 0.03); and • more opportunities to discuss with healthcare professionals (L = 3.60 versus L = 2.28; p = 0.01).	Male patients and male carers have significantly more unmet needs than their female cohorts. Carers of both genders have more unmet needs than patients.
Age[b]	Age correlated negatively with referral to special experts (Spearman correlation 0.29).	Age correlated negatively with: • received rehabilitation and adaptation training (Spearman correlation 0.38); • opportunities to discuss with healthcare professionals (Spearman correlation 0.27); and • received information about the disease, treatment and follow-up (Spearman correlation 0.30).	There are unmet needs among older carers in particular. In both groups, the older the respondent was, the more unmet needs were expressed.
Education[c]	A higher level of education correlated positively with: • received crisis support (p = 0.015); and • psychosocial support (p = 0.023).	A higher level of education correlated positively with[f]: • receipt of more verbal and written information; • receipt of more information about the disease, treatment and follow-up; and • more opportunities to discuss concerns with healthcare professionals.	In both groups, those with lower levels of education have more unmet needs.
Stage of disease[c, d]	There was a statistically significant relationship between the stage of the disease and the sum variable for received information (p = 0.012). Asymptomatic patients in follow-up reported receiving less information than others.	No significant correlation was found between information and support needs and patients' stage of disease.	Patients have high levels of unmet information-related needs, particularly during the follow-up phase of the cancer trajectory.

(*Continued*)

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Table 4. Continued

Characteristics	Patients	Carers	Conclusions
Time since diagnosis[c, e]	Group 2 patients received more rehabilitation and adaptation training ($p = 0.017$) and more information about economic benefits and patient rights ($p = 0.045$) than other groups. Recently diagnosed patients (Group 1) needed more information than other groups ($p = 0.02$).	Time since diagnosis correlated with opportunities to discuss with healthcare professionals: Group 1 had the most opportunities ($L = 3.9$ versus $L = 2.8$ for Group 2 and $L = 2.7$ for Group 3 [$p = 0.021$]). Year of diagnosis did not significantly correlate with information needs.	Among patients, information needs during the follow-up are high. Carers need for support does not correlate with time since diagnosis.

Notes: L refers to mean Likert value (1–5). [a] t-test. [b] Spearman correlation (correlation coefficient provided in parenthesis). [c] One-way analysis of variance. [d] Stage of disease is classified as in Table 1. [e] Time since diagnosis was based on diagnosis year and classified in three groups as in Table 1. [f] For carers, the sizes of the groups were small and no p-values are presented.

healthcare professionals than men. Among patients, women reported that they had received more peer support and had needed more information about the services of cancer organisations.

In both groups, older (≥ 66 years old) participants expressed more unmet needs. Among carers, older participants identified several specific unmet needs, that is, they had received less information and less rehabilitation, and they had had fewer opportunities to talk with healthcare professionals. Older patients also reported that they had received fewer referrals to special experts (for example, those providing psychosocial support).

Carers with higher levels of education reported that they had received more verbal and written information and had had more opportunities to talk with healthcare professionals than carers with less education. Patients with more education reported that they had received more crisis support and psychosocial support than patients with less education.

The disease stage of the patient did not correlate significantly with the information and support needs of the carers. Asymptomatic patients reported that they had received less information during follow-up than other groups, which is probably related to the fact that asymptomatic patients have fewer contacts with healthcare professionals than symptomatic patients.

Among carers, there was a significant negative correlation between time since diagnosis and opportunities for discussion with healthcare professionals. Although recently diagnosed patients reported more opportunities for discussions and had received the most information and support, they still expressed a greater need for information.

Discussion

Key findings

Overall, most patients and carers in our study considered that they had received sufficient information on the cancer illness, on its treatment and on follow-up but

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less information on other matters. Regarding support, there were clear gaps in the amount of support received in both groups. Carers reported that they had received less information and support than patients, and their unmet information and support needs were higher (see Figures 1 and 2 and Tables 2 and 3). The needs expressed by the participants in this study were much higher and much more multifaceted compared with the results in our previous study, which focused on the views of professionals in the Finland Cancer Society (Tiirola et al, 2021). This implies that healthcare providers underestimate the support needs of both groups.

One of the most striking differences between carers and patients was that carers expressed a higher unmet need than patients to discuss their thoughts and feelings about cancer with a healthcare professional (see Figure 2). Thus, it is important for carers to have sufficient opportunities for discussions with healthcare professionals. Thorough and timely face-to-face discussions with healthcare professionals cannot be replaced by written or web-based communication. Addressing these needs would strengthen the support carers can provide for patients, thus benefitting both patients and carers.

Information and support needs: previous findings

Previous studies have emphasised the importance of the timely delivery of information, communication and various kinds of support (for example, Buzaglo et al, 2014; Newby et al, 2015; Li et al, 2020; Bell et al, 2021). In the study of Bell et al (2021), the carers' support needs were classified into four main themes: managing multiple responsibilities; accessing practical support and information; engaging the healthcare system; and maintaining the carer's own health.

While the carers' needs for information about the disease and its treatment, opportunities to talk to professionals, and psychosocial support are recognised, these needs are often incompletely met (Hodgkinson et al, 2007; Wootten et al, 2014; Lehto et al, 2015; Hyun et al, 2016; Zavagli et al, 2022). Wang et al (2018) reported that the most prominent unmet needs of patients are emotional support, fatigue and being informed about the benefits and side effects of treatment. The same study identified a lack of information as the most common unmet need of carers. We also found that the biggest statistical difference between the groups was the need for information (see Table 2 and Figure 1), though receiving information scored higher than receiving different forms of support.

Crotty et al (2020) examined the dynamics of information needs and described the existence of information overload combined with unmet information needs among carers. They also emphasised the role of carers in seeking and sharing information. From the viewpoint of patients, the important indicator of the quality of cancer care is communication, but a lack of psychosocial support may impair the quality of care as well (Vehviläinen-Julkunen et al, 2021).

A recent systematic review summarises the needs of cancer patients and carers in terms of target, content, style, timing and preferences of communication (Li et al, 2020). Communication content includes illness-related communication, emotional support, daily life, sexuality and death. The timing of communication is exceptionally important before treatment and approaching death. The authors conclude that patients and carers have different communication needs, and a better understanding of the

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unique communication needs of patients and carers will provide health professionals with detailed information on designing appropriate interventions to support cancer patients and carers.

The results of the present study corroborate, in general, these previous findings. However, the present findings particularly highlight the high unmet needs of supporting carers, especially through better discussion opportunities and more peer support. Our results underline the higher and statistically significant unmet needs of carers compared to patients, a finding that was not as clear in previous studies – few of which have conducted direct, versatile statistical comparisons of these two groups.

Information and support needs: general well-being

Well-being is a complex and subjective concept and encompasses physical, psychosocial and social domains. In the current context, health is usually a prominent factor. We found that patients who felt that they had received enough information and support reported significantly better general well-being than patients who felt that they had not received enough information and support. These findings on the importance of information and support for the well-being of patients may even be understated, as the most important reason for non-participation in our study was poor general health. These findings emphasise the need for more research explicitly on the well-being and quality of life of those who care for cancer patients.

White et al (2019) observed that healthcare professionals may not recognise caring relationships as a clinical matter or as a priority. Healthcare professionals may not take into consideration the needs and overall well-being of the carers, which means that the support offered to patients is not always provided to carers (Carduff et al, 2014; 2016). Caring is associated with a potential negative impact on several domains of the carers' life: health, life satisfaction and ability to maintain everyday activities (Rand et al, 2020).

When the support needs of prostate cancer patients and their carers were investigated, carers reported at least one unmet need relating to 'enabling the carers to care' and relating to 'the carers' own well-being'. Carers with chronic illnesses had more unmet needs than healthy carers (Johnson et al, 2021). As the population ages, the proportion of carers with poor health and chronic illnesses will increase, which further emphasises the need for increasing the support for carers of cancer patients. Examining the unmet needs based on viewing patients and their informal carers as an entity has been considered optimal (Wang et al, 2018).

Need for information and support: explanatory variables

In our study, we found that the need for information and support was associated with gender, age, level of education and time since diagnosis. Males and older and less educated individuals in both groups reported a higher need for information and support, and this difference was particularly marked among carers (see Table 4). One striking finding was that male patients, and even more so male carers, expressed a significantly higher need for various forms of information and support, including peer support and discussions with healthcare professionals. In one systematic review

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(Lambert et al, 2012), female caregivers expressed more needs in this respect, but a large questionnaire study by Veloso et al (2013) found that male gender, low educational level and living alone were linked to the unmet needs of patients. There is also some evidence that male carers are less likely to seek help, which may be related to an attitude of commitment to the role of carer combined with a sense of duty or responsibility and insufficient information (Greenwood et al, 2015). Thus, more emphasis should be put on the needs of male carers, who should also be encouraged to seek support.

In our study, older individuals expressed more need for various forms of information and support; this was particularly the case for carers. This finding is in line with the finding by Baudry et al (2019), who conclude that a combination of three main variables significantly predicts the risk for carers having unmet needs for supportive care: symptoms of anxiety and/or depression; the age of carers or patients; and the presence/absence of metastases. Older participants may need information on other forms of support than what is currently available, and they may find accessing digital information difficult. To overcome this, healthcare professionals should focus more on older patients' personal needs and information needs (Launonen et al, 2021). Such needs may be related to a double disease burden, like dementia and cancer (Price et al, 2022).

Our results also showed – as expected – that a greater need for information was expressed by recently diagnosed patients, despite the fact that these patients usually receive the most support. Patients' needs also change over time (Halbach et al, 2016). Interestingly, we found that the time since diagnosis was not related to the support needs of carers. Girgis et al (2011) reported that although the prevalence of unmet needs significantly decreased among carers over time, almost one third still reported unmet needs 24 months after diagnosis. These findings highlight the need for prolonged support for carers.

Strengths and limitations

The reliability and external and internal validity of the present study were evaluated. The number of responses to the questionnaires was sufficient for the statistical analyses presented here (Kellar and Kelvin, 2013). The external validity of the study was good (Gray et al, 2017). There was no selection of participants. Instead, all participants had equal opportunities to participate, and the opportunity to participate was long enough. Overall, these measures ensured comprehensive data.

Reliability was enhanced by selecting factors from previous cancer patient studies. Our data include a discretionary sample of patients with common types of cancer. All types of cancer patients and carers were included to identify general themes around unmet needs. To increase the generalisability of the results, we collected data from several wards of a large university hospital covering a large catchment area. The missing data analysis indicated that the data were representative.

The study also has some clear shortcomings. Since sampling was by self-selection, the level of inference cannot be generalised to the population. We did not use validated questionnaires; instead, we asked the same questions from diverse groups to enable comparisons, namely patients, carers and healthcare professionals (not yet reported). Although all reasonable efforts were made to inform suitable participants about the study and to encourage participation, there were limitations in terms of who received

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the questionnaire and how actively the healthcare professionals provided information about the study alongside their daily duties. Therefore, it cannot be stated that this sample is representative of the entire population. For example, patients in the palliative phase were not well represented due to poor overall health. The sample size was still limited and not all participants answered all questions, though internal data loss was evenly distributed among the different groups of participants.

Implications of the study for developing support services

Our findings indicate that healthcare professionals focus primarily on caring for patients and the patients' immediate information and support needs. The needs of the carers often remain unrecognised and hence unaddressed. This is also reflected in the grossly different and unequal positions of carers versus patients in the service system: carers are not the clients of healthcare professionals.

A range of support needs were recognised, including for psychosocial support, thus requiring a more prominent role of health professionals like social workers and physiotherapists. Only a few of our participants had received referrals to these experts. The needs of both cancer patients and their carers are such that cancer support should be portrayed as truly multi-professional work that considers the various individual needs of patients and their carers at different stages of the cancer disease.

Our study identifies specific groups in need of more support: male patients and particularly male carers. Healthcare professionals should also provide more effective guidance for vulnerable patient groups, including older carers and those with poor health literacy. The individual support needs of cancer patients and carers should be systematically assessed and addressed at different phases of the cancer trajectory (for example, Holm et al, 2012; Handberg et al, 2017; Jolliffe et al, 2019). These efforts are necessary to identify the support needs of carers more effectively, both for cancer and other disease categories.

Our findings also indicate that carers should be more actively involved and have their voices heard in the treatment pathways of cancer patients as a means to develop and improve services for all. Simple, inexpensive interventions, such as peer support, could benefit both groups.

Effective, high-quality and timely information and support will help patients and their carers to cope better with the cancer disease. Adequate delivery of information and support should begin from diagnosis and should remain a key element of care throughout the entire cancer trajectory.

Conclusions

Most patients and carers in our study considered that they had received information sufficiently on illness, treatment and follow-up but less on other forms of information. Both patients and carers reported that they had received proportionately less support than information, and carers reported that they had received less information and support than had patients.

In both groups, but particularly among carers, the unmet needs for information and support were multifaceted and most profound among older individuals, among those with a lower level of education and among males. Our results emphasise the

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overall need for a multidisciplinary approach to the identification of support needs and the delivery of support throughout the entire cancer care pathway.

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Note

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Conflict of interest

The authors declare that there is no conflict of interest. Dr Päivi Auvinen and Dr Kristiina Tyynelä-Korhonen are employees at the University Hospital of Kuopio, where the questionnaire study was conducted.

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