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Supportive care needs and the use of supportive care services from diagnosis to one year after radical cystectomy in patients with bladder cancer: a longitudinal cohort study

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Supportive care needs and the use of supportive care services from diagnosis to one year after radical cystectomy in patients with bladder cancer: a longitudinal cohort study

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ABSTRACT

Objectives

Investigating supportive care (SC) needs and utilization/willingness to use SC services from diagnosis to one year after radical cystectomy (RC) in bladder cancer (BC) patients.

Materials & Methods

A longitudinal cohort study was conducted in 90 BC patients at Ghent/Leuven University Hospitals between April 2017 and December 2020. The Supportive Care Needs Survey-short form (SCNS-SF34) was used before RC, one, three, six and twelve months after RC. Additional questions assessed utilization/willingness to use SC services. Linear mixed models were performed.

Results

The majority of MIBC patients report at least one moderate or high SC need at diagnosis (82%), month 1 (84%), month 3 (86%), month 6 (64%), and month 12 (60%). Significant changes over time were seen for all domains($p<0.001$), except for sexuality($p=0.275$). Psychological (e.g. fears about the future) and informational (e.g. information on how to get better) needs were most common at baseline whereas physical (e.g. lack of energy) and informational needs were more common in the early postoperative phases. The majority of patients (ranging from 81% (month 1) to 91% (month 12)) did not make use of services and the majority of the patients (ranging from 81% (month 1) to 88% (month 12)) did not wish to talk about their problems to someone. Those willing to talk to someone preferred their physician.

Conclusions

MIBC patients need to be empowered and made aware of the services available to seek the help that they need throughout their care pathway. Information provision should be key in future SC interventions for MIBC patients.

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INTRODUCTION

Diagnosis and treatment of bladder cancer (BC) causes worse patient experiences in comparison with other cancer groups (1). Muscle-invasive BC (MIBC) patients are faced with complex and unique needs (2, 3). MIBC patients are usually treated with neoadjuvant chemotherapy, followed by a radical cystectomy (RC) with a urinary diversion procedure and pelvic lymph node dissection (4). Patients can also be offered a bladder preserving alternative with a combination of radio- and chemotherapy if appropriate (4).

These radical treatments are associated with a variety of physical and psychosocial side-effects which may lead to several supportive care (SC) needs (5). SC needs are often categorized in the following six domains: informational, emotional, psychosocial, practical, spiritual, and physical needs (6). These needs can be present at any time during the cancer trajectory: from diagnosis to completion of treatment, recurrence of disease and death (7).

The limited research focused on MIBC patients has shown unique SC needs that are specific to this population. Results of both qualitative and quantitative cross-sectional studies have suggested that adapting to a new urinary diversion is difficult and requires specific self-management skills (e.g., manual dexterity) (8). Informational needs are commonly reported at time of diagnosis, whereas SC needs related to challenges in self-care skills (e.g., utility of stomal appliances and catheters) are reported after treatment. Physical needs related to symptoms such as fatigue or pain are also reported in this vulnerable population (9). In addition, MIBC patients experience psychological needs as feelings of anxiety or depression are often neglected during clinical consultations (8). Furthermore, sexual needs have frequently been reported in patients with BC and are infrequently explored during early clinical consultations with the physicians or post-treatment follow-up care (8).

In order to prevent and reduce the negative patient experiences in MIBC, patients can be offered appropriate SC services. SC is a patient-centred approach aiming to respond to patients' informational, emotional, social, spiritual or physical needs during their cancer trajectory (6). However, healthcare providers often lack awareness of available resources for provision of SC and many cancer patients do not receive sufficient support or care to adjust and cope with the challenges associated with diagnosis and treatment of cancer (10, 11). In addition, it is not clear whether patients are willing to use SC services during their illness trajectory.

Several studies have investigated the SC needs in cancer patients. However, BC patients remain an understudied, yet important patient population in this area of research (8). Although some studies examined the SC needs of MIBC patients, to our knowledge all studies to date are cross-sectional (8). No research has examined changes in SC needs over the MIBC trajectory. Examining changes in SC needs is important to inform the design of future SC programs to timely address MIBC patients' needs.

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In addition, it is important to investigate current utilization of SC services and the willingness of patients to use such services. Therefore, this study examined the SC needs and the utilization and willingness to use SC services in MIBC patients from diagnosis to one year after RC.

METHODS

Study design

A multicentre longitudinal cohort study was conducted with survey measurements scheduled before RC (timeframe of four weeks before RC) (T1), one month (T2), three months (T3), six months (T4) and twelve months after RC (T5). The study protocol was registered at clinicaltrials.gov (NCT03307200) and approved by the ethical committee of Ghent University (EC/2017/1362) and University Hospitals Leuven (S61059). The reporting of this manuscript adheres to the STROBE checklist for cohort studies.

Participants

Patients were eligible if they were aged 18+ years, diagnosed with MIBC and scheduled for a RC at Ghent University Hospital or the University Hospital Leuven, metastasis free at diagnosis, had no second primary tumour at diagnosis (except removed prostate cancer or non-melanoma skin tumour and a tumour diagnosed more than five years ago and being under control) and were capable to sign and understand the informed consent.

Data collection and measurements

Patients were recruited at the Urology department from Ghent University Hospital and the University Hospital Leuven between April 2017 and December 2019. Data collection was completed in December 2020. After written informed consent, patients filled in a paper-pencil version of the Dutch Supportive Care Needs Survey-short form (SCNS-SF34), and some additional questions about utilization and willingness to use SC services. Patients repeated this at each time point.

The Dutch version of the SCNS-SF34 is a valid and reliable instrument to measure SC needs in cancer patients (12, 13). The instrument includes five subscales or domains(14): Psychological (10 items), Health System and Information (11 items), Physical and Daily Living (5 items), Patient Care and Support (5 items), and Sexual (3 items) care needs. To rate the intensity of each need, the instrument includes a 5-point Likert response scale (1 = Not applicable, 2 = Satisfied, 3 = Low need, 4 = Moderate need, and 5 = High need). A total score for each subscale was computed using standardized scores, which ranged from 0 to 100. Higher scores reflect higher SC needs and vice versa.

In addition, questions were asked to collect information regarding the use of SC services and the willingness to talk to someone or to use SC services. An example of the English translated questionnaire

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can be found in supplementary file 1. Demographical and clinical data was also collected using a case report form.

Statistical analyses

A sample size of 40 patients per institution was required to obtain a 95% Wilson score statistic based confidence interval with a precision of +/- 15% or better around the prevalence estimates, with >99% probability of achieving the desired precision. Taking into account a dropout rate of 10%, a total sample size of at least 44 patients per institution was required. Two institutions took part in this study which required a total sample size of at least 88 patients (equally balanced).

Statistical analyses were carried out in SPSS Statistics 25. Descriptive statistics were used to describe the sample characteristics. Percentages of MIBC patients experiencing at least one SC need were calculated for each time-point. Prevalence of the single-items within each SC needs domain was calculated (percentages) to understand the SC needs in more detail. Descriptions of the levels of SC needs at each time point included percentages of patients having 'no need' (indicated in the questionnaire as not applicable or satisfied), 'low need', 'moderate need' , or 'high need'.

To investigate changes in SC needs from diagnosis to one year after radical cystectomy, linear mixed models with autoregressive structure were used. According to the scoring recommendations by Boyes et al. (15), summated scores between 0 and 100 (higher numbers indicate higher needs) were created to examine changes over time in the different domains. If less than half of the items within a domain were missing, the mean of the other items in that domain was imputed for the missing items (15). The means and changes of the sum scores of each domain were visually presented in a line graph. The additional questions about the use and willingness to use SC services were summarized descriptively.

RESULTS

In total, 103 eligible patients were invited to participate, of whom 90 (response rate of 87%) were willing to be included in this longitudinal study. The percentage of missing data was 8%, 18%, 23%, 22% and 30% at baseline, month 1, 3, 6 and 12, respectively. Missing data was partly due to patient withdrawal (n=5), disease progression (n=2) and death of participants (n=10). Other reasons for missing data throughout the time-points were: patients not sending back the questionnaire with unknown reason, administrative failure, patients returning a blank questionnaire, concentration problems, and not willing to complete the questionnaire. Demographical and clinical patient characteristics are presented in table 1.

Supportive care needs

Prevalence of supportive care needs

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The majority of MIBC patients report at least one moderate or high SC need at diagnosis (82%), month 1 (84%), month 3 (86%), month 6 (64%), and month 12 (60%). A detailed overview of the prevalence of all single-item SC needs is shown in supplementary file 2. The top 5 most common moderate or high single-item SC needs across all domains at each timepoint are summarized in Table 2.

Sum scores and changes over time

At baseline, the psychological and informational needs indicated the highest sum scores followed by the sum scores of the physical needs. At month one, informational needs remained most common together with the physical needs (and followed by the psychological needs). At month three, six and twelve, informational, physical and psychological needs were most common while patient care needs and sexual needs were least common across all time points. The estimated means and changes of the sum scores of each domain are presented in Figure 1.

Significant changes over time were seen for psychological needs ($p<0.001$), informational needs ($p<0.001$), physical and daily living needs ($p<0.001$), and patient care and support needs ($p=0.001$). Changes over time for sexual needs were not statistically significant ($p=0.275$). Table 3 presents the estimated mean differences from baseline, 95% confidence intervals and p-values for the different time-points.

Utilization of and willingness to use supportive care services

The majority of the patients (ranging from 82% (month 1) to 91% (month 12)) did not make use of an additional SC service. Of those that did not use SC services, most patients indicated they did not talk about additional SC services during the consultation with their physician (ranging from 81% (month 1) to 89% (month 12)). Hence, most patients indicated (ranging from 91% (baseline) to 98% (month 6)) this was not experienced as a shortcoming.

Furthermore, the majority of the patients (ranging from 81% (month 1) to 88% (month 12)) did not wish to talk about their problems to someone. Those willing to talk to someone preferred their physician.

Patients who did make use of an additional SC service went to a psychologist (n=6), a dietician (n=5), or an exercise program (n=2) at baseline. At month 1, patients went to see a psychologist (n=5), a dietician (n=10), or attended an exercise program (n=2). At month 3, patients visited a psychologist (n=1), or attended an exercise program (n=4). At month 6, patients went to see a dietician (n=3) or attended an exercise program (n=3). At month 12, patients visited a psychologist (n=1) or attended an exercise program (n=1).

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DISCUSSION

In this study we investigated the SC needs of MIBC patients from diagnosis to one year after RC and the current utilization and willingness of BC patients to use SC services. The majority of MIBC patients report at least one moderate or high SC need at diagnosis (82%), month 1 (84%), month 3 (86%), month 6 (64%), and month 12 (60%). Psychological and informational needs were most common at baseline, whereas physical and informational needs were most common in the first month after RC. At month three, six and twelve, psychological, informational and physical needs were similar. Patient support and sexuality needs were least common across all time-points. Throughout all time points, psychological needs were mainly related to fears and concerns about the future, while physical needs were mostly related to a lack of energy or not being able to perform day-to-day tasks that patients are used to do. The informational needs were mostly related to getting information about whether the cancer is under control and information about what one can do to get better again. Although the needs of MIBC patients decreased over time, there were still patients experiencing moderate or high SC needs one year after RC. In contrast, more than 80% is not using and is not willing to use SC services across all time-points and SC services were discussed during clinical consultations in less than 20% of the cases across all time-points.

Compared to published reference data for cancer survivors five to nine months post diagnosis(16), our study cohort in BC patients showed higher sum scores for all SC need domains. Also, a previous paper by Boyes et al.(17) in a mix of cancer patients six month post diagnosis showed that 37% reported at least one moderate or high SC need whereas the percentage of BC survivors six months after RC reporting at least one moderate or high SC need in our population was 64%(17). However, in the study by Boyes et al.(17) lung cancer patients reported the highest percentage for at least one moderate or high SC need (60%) which is more comparable to our findings in BC patients(17). The type of most prevalent SC needs also differed between the previous study and our study in BC patients(17). Items from the informational domain were not present in the top ten most common SC needs in the study by Boyes et al.(17) whereas in BC patients two single-items from the informational domain were in the top five most common SC needs at month six after RC. Type of psychological and physical needs were similar (e.g. fears about the cancer spreading, uncertainty about the future and lack of energy/tiredness) but were more prevalent in our BC study (for example, 15% versus 25% for fears about the cancer spreading and 12% versus 23 % for lack of energy/tiredness)(17).

The fact that psychological needs are most important during the preoperative period is not surprising because receiving a diagnosis of cancer, making life changing treatment decisions (ileal conduit versus neobladder) and awaiting major cancer surgery cause a lot of psychological distress (18). A previous study found that 44.6% of MIBC patients experience psychological distress at diagnosis, which is higher than in other cancer populations (7). In several cases, there is a long time between the first complaints

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and the diagnosis of BC. This increases the likelihood that BC will progress to a further stage, which puts additional pressure on the patients' psychological well-being (19, 20). In line with other studies, our results also showed that psychological needs are mostly related to uncertainties and fears about the future (e.g. recurrence, cancer spreading) (8). Psychological needs decrease after baseline, but remain important over time because at month three, six and twelve, items present in the psychological domain were still in the top 5 of most commonly reported moderate to high SC needs.

At month 1, physical needs became most important. In the early postoperative period, patients are faced with a new urinary diversion, while they also have to recover from major cancer surgery and neoadjuvant chemotherapy (4, 21). This causes physical challenges with trial and error (21). In addition to these physical needs, patients also experience a lot of informational needs in the early postoperative period. Because of the complexity of this period, the required self-management skills related to their urinary diversion, and the possible side-effects affecting patients' ability to learn about self-care (e.g. pain, fatigue, anxiety), patients need sufficient and clear information about the things they can do to get well again (3, 21).

Hence, informational needs were most commonly reported across all time points. The fact that patients mainly want sufficient and clear information might explain the discrepancy in our results between the presence of SC needs and the non-utilization and willingness to use SC services. It is possible that providing patients with sufficient and clear informational resources can also help to reduce other supportive care needs (e.g. psychological, physical). The physician was also most often reported as person to talk to which again indicated that information from a clinician is important. Other possible explanations for not using SC services are the following: not recognizing their own problems, not understanding or knowing that their problems can be treated, a preference to self-manage or use informational sources of support and patient limitations that might act as a barrier to accessing SC services(22).

Implications for clinical practice and research

The results of this study have several important implications for clinical practice as well as for the research community. Although it is probably not possible to completely eliminate some SC needs (e.g. need to receive test results faster, fear of cancer recurrence), supportive interventions can provide the patients with tools to help deal with certain needs.

Future interventions, in clinical practice as well as in a research context, must aim to reduce uncertainties and fears about the future. Recent evidence shows that mind-body interventions such as cognitive behaviour therapy or meditative exercises are efficacious to reduce fear of cancer recurrence(23). Because psychological needs may differ between patients and over time, screening patients for psychological distress can be helpful to identify patients at risk (24). However, screening patients for distress and referring them to psychosocial services might not be sufficient to decrease patients'

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psychological needs(25). In order to address psychological needs, other strategies than referrals to psychosocial services must be used. Healthcare providers, especially nurses and clinicians, should be trained to address BC patients' psychological needs because they play a key role during patients' illness trajectory and are also the patients' first point of contact (18, 26).

The physical and daily living needs in the early postoperative period are mostly due to the patients' physical condition (i.e. lack of energy, not able to do the things they are used to do, work around the home). These issues can potentially be reduced if patients engage in sufficient physical activity before and after radical cystectomy (27). Especially the preoperative period can be seen as a 'window of opportunity' because patients' motivation to engage in sufficient physical activity can be bigger if they feel it could improve their postoperative outcomes (28). Furthermore, prehabilitation programs have the potential to improve postoperative physical and mental wellbeing of cancer patients (29-31). A study by Jensen et al. showed that a multimodal prehabilitation program (including preoperative exercise) improves postoperative activities of daily living in BC patients (32).

Informational needs can also be reduced by giving sufficient education in the preoperative period (33, 34). Because the patients' ability to manage their urinary diversion influences their recovery and health-related quality of life, providing the patient with sufficient and clear information must be a priority in the BC pathway (21). Education on the important aspects of BC care should be repeated or should be offered through an easily accessible channel because the early postoperative side-effects experienced by BC patients can influence their ability to absorb relevant information(21).

Strengths and limitations

The major strength of this study is the fact that it is the first study using a prospective design to longitudinally assess SC needs in MIBC patients. The relative small sample size allowed us to make conclusions about the proportions of needs at the different time-points, though may not have been large enough to identify differences in demographical/clinical characteristics with sufficient statistical power (type 2 error)(35).

This study used the SCNS-34, which is a cancer-specific questionnaire (14). Although some of the informational and psychical needs can be related to specific MIBC issues, a questionnaire assessing MIBC-specific needs, would have been more specific. However, at the beginning of our study, there was no MIBC or BC specific questionnaire available to measure needs. After the start of this study, a study was published which validated a BC specific questionnaire (36). This questionnaire uses the same domains as the SCNS-34, but the items within the domains are more focused on BC specific outcomes. It is recommended that future studies use this BC specific questionnaire to assess SC needs in BC (36). Furthermore, this study only focused on the SC needs of the MIBC patients. In future studies, caregivers should also be taken into account as they are also faced with various challenges throughout the MIBC trajectory (3). Finally, no evidence exists for the clinical relevance of the sum scores or important cut-

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off values for the sum scores of the SC need domains used. This makes it difficult to interpret our results and the clinical relevance of differences in sum scores between time points. Future research must provide guidelines on how to interpret sum scores of the SCNS-34 (37).

Conclusions

The majority of MIBC patients experience at least one moderate or high SC needs from diagnosis (82%) to one year (60%) after surgery. Type and level of SC needs reported by MIBC patients changed over the first year following diagnosis and treatment, with patients being more likely to experience significant informational (e.g. information on how to get better again), psychological (e.g. fears about the future), and physical needs (e.g. lack of energy) at all time-points. Moreover, the majority (>80%) is not using and is not willing to use SC services across all time-points and SC services were rarely (<20%) discussed during clinical consultations across all time-points. MIBC patients need to be empowered and made aware of the services available to seek the help that they need throughout their care pathway. Information provision should be key in future SC interventions for MIBC patients.

CONFLICT OF INTEREST

None.

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TABLES

Table 1 patient characteristics (N=90)

Demographical information	
Gender: n(%)	
Men	74(82%)
Age (Mean ±SD)	69±10
Marital status: n(%)	
No partner	3 (3%)
Married or living as married	66 (73%)
Widowed	6 (7%)
Divorced	8 (9%)
Missing	7 (8%)
Education level: n(%)	
Primary school	13 (14%)
Secondary school	36 (40%)
Bachelor's degree	18 (20%)
Master's degree	10 (11%)
Other	1 (1%)
Missing	12 (13%)
Employment status: n(%)	
Full-time	10 (11%)
Part-time	2 (2%)
Retired	66 (73%)
Volunteering work	5 (6%)
Missing	7 (8%)
BMI: n(%)	
Underweight	17 (19%)
Normal weight	49 (54%)
Overweight	13 (15%)
Missing	11 (12%)
Smoking status: n(%)	
Non-smoker	21 (23%)
Smoker	15 (17%)
Ex-smoker	43 (48%)
Missing	11 (12)
Clinical and treatment information	
Charlson Co-morbidity index (mean±SD)	5.8±2.8
Preoperative T-stage TURBT: n(%)	
Ta-Tis	8 (9%)
T1	9 (10%)
T2	27 (30%)
T3	28 (31%)
T4	9 (10%)
Urinary diversion type: n(%)	
Ileal conduit	64 (71%)
Neobladder	25 (28%)
Mainz Pouch	1 (1%)
Neoadjuvant chemotherapy: n(%)	46 (51%)
Adjuvant radiotherapy: n(%)	23 (26%)

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Table 2 top 5 unmet moderate to high supportive care needs

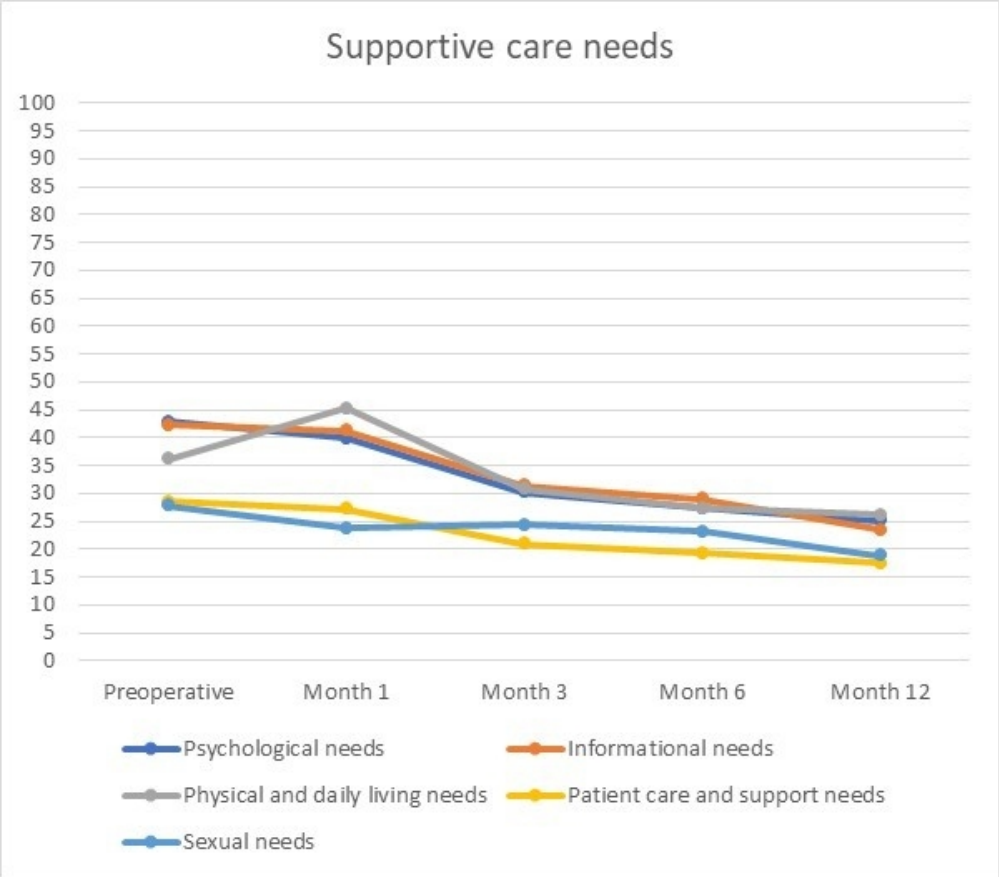
Rank	Unmet need	Percentage (95%CI)	Numbers (n/nTotal)	Domain
Baseline				
1	Uncertainty about the future	45 (35 to 56)	(37/82)	Psychological
2	Fears about the cancer spreading	43 (33 to 54)	(36/83)	Psychological
3	To be informed about things you can do to help yourself get well	42 (32 to 53)	(35/83)	Health system & Information
4	To be informed about cancer which is under control or diminishing (that is, remission)	41 (31 to 52)	(34/83)	Health system & Information
5	Worry that the results of treatment are beyond your control	39 (29 to 50)	(32/82)	Psychological
Month 1				
1	Lack of energy/tiredness	48 (36 to 59)	(33/70)	Physical and daily living
2	Not being able to do the things you used to do	47 (36 to 59)	(34/72)	Physical and daily living
3	To be informed about things you can do to help yourself get well	39 (28 to 50)	(28/72)	Health system & Information
4	Work around the home	38 (27 to 50)	(24/64)	Physical and daily living
5	To be informed about cancer which is under control or diminishing (that is, remission)	38 (28 to 49)	(28/74)	Health system & Information
Month 3				
1	To be informed about cancer which is under control or diminishing (that is, remission)	28 (19 to 40)	(19/68)	Health system & Information
2	To be informed about things you can do to help yourself get well	23 (15 to 34)	(16/69)	Health system & Information
3	To be informed about your test results as soon as feasible	22 (14 to 33)	(15/69)	Health system & Information
4	Fears about the cancer spreading	22 (14 to 34)	(15/67)	Psychological
5	Not being able to do the things you used to do	22 (14 to 34)	(15/67)	Physical and daily living
Month 6				
1	Fears about the cancer spreading	25 (16 to 36)	(17/69)	Psychological
2	To have one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	24 (16 to 36)	(17/69)	Health system & Information
3	To be informed about cancer which is under control or diminishing (that is, remission)	23 (15 to 34)	(16/69)	Health system & Information
4	Uncertainty about the future	23 (15 to 34)	(16/70)	Psychological
5	Lack of energy/tiredness	23 (15 to 34)	(16/70)	Physical and daily living
Month 12				
1	Lack of energy/tiredness	25 (16 to 37)	(15/60)	Physical and daily living
2	Fears about the cancer spreading	19 (11 to 31)	(12/62)	Psychological
3	Not being able to do the things you used to do	16 (9 to 27)	(10/63)	Physical and daily living
4	To be informed about your test results as soon as feasible	16 (9 to 27)	(10/63)	Health system & Information
5	Work around the home	14 (7 to 25)	(8/59)	Physical and daily living

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Table 3 differences from baseline

Time-point	Mean difference	95% CI		p-value
		Lower bound	Upper bound	
Psychological needs				
Month 1	-2.987	-8,057	2,084	.247
Month 3	-12,699	-19,085	-6,313	.000
Month 6	-15,494	-22,519	-8,469	.000
Month 12	-17,812	-25,382	-10,241	.000
Informational needs				
Month 1	-1,074	-6,365	4,217	,690
Month 3	-10,923	-17,341	-4,506	,001
Month 6	-13,325	-20,181	-6,469	,000
Month 12	-18,867	-26,118	-11,616	,000
Physical and daily living needs				
Month 1	9,134	3,715	14,554	,001
Month 3	-5,363	-12,142	1,416	,121
Month 6	-8,747	-16,183	-1,311	,021
Month 12	-10,060	-18,067	-2,052	,014
Patient care and support needs				
Month 1	-1,306	-5,648	3,037	,554
Month 3	-7,555	-12,752	-2,359	,004
Month 6	-9,254	-14,741	-3,767	,001
Month 12	-11,006	-16,773	-5,238	,000
Sexual needs				
Month 1	-4,060	-10,029	1,910	,182
Month 3	-3,473	-10,819	3,873	,353
Month 6	-4,613	-12,643	3,416	,259
Month 12	-9,015	-17,616	-,413	,040

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127x111mm (120 x 120 DPI)

Supplementary file 1: detailed overview of all items (%) whereas 0= no need, 1=low need, 2=moderate need, and 3=high need

	Baseline				Month1				Month3				Month6				Month12			
Psychological	0	1	2	3	0	1	2	3	0	1	2	3	0	1	2	3	0	1	2	3
Anxiety	54	19	17	10	75	7	13	4	79	8	13	0	85	9	1	5	81	13	6	0
Feeling down or depressed	57	23	12	8	66	16	12	6	80	7	13	0	84	7	6	3	82	13	3	2
Feelings of sadness	54	21	14	11	64	22	7	7	82	7	9	2	81	9	7	3	86	6	5	3
Fears about the cancer spreading	35	22	18	25	41	20	22	16	60	18	13	9	56	19	19	6	55	26	16	3
Worry that the results of treatment are beyond your control	43	18	23	16	46	28	15	11	57	25	12	6	67	13	16	4	62	24	11	3
Uncertainty about the future	31	24	22	23	41	23	24	12	49	28	18	4	56	21	14	9	57	29	8	6
Learning to feel in control of your situation	44	22	21	13	49	18	25	7	64	21	14	1	68	20	9	3	82	11	5	2
Keeping a positive outlook	56	16	15	13	62	22	8	8	77	12	9	3	84	9	6	1	89	8	2	1
Feelings about death and dying	60	14	15	11	74	14	8	4	75	10	9	6	83	7	9	2	84	9	5	2
Concerns about the worries of those close to you	46	25	11	18	47	22	19	12	59	16	7	7	66	14	13	7	68	19	11	2
Health system & Information	0	1	2	3	0	1	2	3	0	1	2	3	0	1	2	3	0	1	2	3
To be given written information about the important aspects of your care	69	14	10	7	69	8	16	7	76	12	10	2	84	6	9	1	92	5	2	1
To be given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	63	10	15	12	60	16	11	12	78	12	9	1	81	7	9	3	90	5	3	2
To be given explanations of those tests for which you would like explanations	66	13	8	12	62	15	12	11	70	10	16	4	80	9	7	4	84	6	2	8
To be adequately informed about the benefits and side-effects of treatments before you choose to have them	69	7	10	14	65	11	13	11	71	11	12	6	74	10	10	6	84	3	5	8
To be informed about your test results as soon as feasible	57	10	14	18	47	16	19	18	67	11	12	10	73	6	11	10	76	8	8	8
To be informed about cancer which is under control or diminishing (that is, remission)	52	7	14	27	58	4	16	22	60	12	16	12	68	9	7	16	81	6	3	8
To be informed about things you can do to help yourself get well	48	10	24	18	49	12	26	13	62	15	17	6	70	9	12	9	76	13	6	5
To have access to professional counselling (eg, psychologist, social worker, counsellor,	61	17	17	6	64	15	17	4	78	12	7	3	84	4	12	0	86	5	9	0

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nurse specialist) if you/family/friends need it																				
To be treated like a person, not just another case	65	5	10	20	75	10	11	4	77	6	13	4	83	1	10	6	92	3	3	2
To be treated in a hospital or clinic that is as physically pleasant as possible	66	8	11	15	69	17	10	4	83	4	12	1	79	3	12	6	92	2	2	1
To have one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	58	7	17	18	52	21	18	9	73	10	10	7	71	4	17	7	90	5	3	2
Physical & daily living	0	1	2	3	0	1	2	3	0	1	2	3	0	1	2	3	0	1	2	3
Pain	71	11	11	7	67	19	4	10	82	10	8	0	77	13	4	6	82	5	11	2
Lack of energy/tiredness	47	15	21	17	31	21	29	19	59	19	19	3	57	20	17	6	65	10	22	3
Feeling unwell	64	16	11	9	57	21	18	4	78	10	10	2	84	7	6	3	89	5	6	0
Work around the home	62	14	13	10	52	11	16	22	64	21	11	4	66	18	14	2	76	10	7	7
Not being able to do the things you used to do	47	18	12	23	33	19	22	25	55	22	13	9	62	22	10	6	73	11	5	11
Patient care & support	0	1	2	3	0	1	2	3	0	1	2	3	0	1	2	3	0	1	2	3
More choice about which cancer specialist you see	73	10	9	8	86	9	4	1	84	7	7	2	83	10	7	0	90	2	5	3
More choice about which hospital you attend	87	6	4	3	93	4	3	0	90	4	4	2	94	4	1	0	95	2	1	2
Reassurance by medical staff that the way you feel is normal	74	12	6	8	74	11	12	3	77	14	7	2	80	7	12	1	82	5	10	3
Hospital staff to attend promptly to your physical needs	78	6	10	6	76	9	10	5	86	7	7	0	91	6	0	3	90	2	5	3
Hospital staff to acknowledge, and show sensitivity to, your feelings and emotional needs	81	5	10	5	78	8	11	3	87	6	7	0	95	4	1	0	90	5	3	2
Sexuality	0	1	2	3	0	1	2	3	0	1	2	3	0	1	2	3	0	1	2	3
Changes in sexual feelings	63	17	11	9	69	14	14	3	64	19	12	6	71	17	3	9	74	17	7	2
Changes in sexual relationships	65	16	9	10	73	13	11	3	68	16	10	6	75	13	4	7	77	14	7	2
To be given information about sexual relationships	76	10	11	3	75	16	8	1	80	10	6	4	74	18	6	2	89	3	8	0

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