

TITLE: Association between information provision and supportive care needs among ovarian cancer survivors: A cross-sectional study from the PROFILES registry

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ABSTRACT

OBJECTIVE: To examine the association between satisfaction with perceived information provision during diagnosis and treatment and supportive care needs in ovarian cancer survivors.

METHODS

In 2012, women (n=348) diagnosed with ovarian cancer, as registered between 2000 and 2010 in the Netherlands Cancer Registry, received a questionnaire including questions on the perceived level of, and satisfaction with, information received (EORTC QLQ-INFO25) and supportive care needs (Cancer Survivors' Unmet Needs Measure).

RESULTS

Of 348 women, 191 (55%) responded. Of all participants, 35% were not satisfied (n=65) with the perceived amount of information received. Participants who were satisfied with the amount of information reported significantly higher levels of perceived information on disease, medical tests, treatment and other services. Patients not satisfied with information provision had a higher total number of needs and a higher number of unmet needs than women satisfied with information provision. Multivariable linear regression analysis showed that satisfaction with information provision was negatively associated with the total number of unmet needs ($\beta=-0.20$, $p=0.03$) after adjustment for potential confounding clinical and socio-demographic factors.

CONCLUSION

Ovarian cancer survivors, satisfied with the information provision during treatment reported fewer unmet needs during survivorship. Optimization of information provision for ovarian cancer patients during initial diagnosis and treatment may contribute to a decrease in unmet needs during survivorship.

INTRODUCTION

Ovarian cancer is the third most common gynecological malignancy worldwide [1]. In the Netherlands, about 1.300 women are diagnosed with ovarian cancer annually [2, 3]. Due to non-specific symptoms, the disease is usually diagnosed at an advanced disease stage (up to 70% of patients are diagnosed with stage III/IV disease) with extensive involvement of the abdominal cavity [4]. Primary treatment usually consists of surgery or a combination of surgery and chemotherapy. Although primary treatment is successful in most cases, 75% of patients will get recurrent disease and die within 5 years [5]. Less than 27% of patients will survive 5 years or more [3].

Ovarian cancer places a heavy emotional and physical burden on patients [6]. The most frequently reported problems are fatigue, pain, neuropathy, concerns about recurrence, progression and death, managing treatment side-effects, worries about running out of options for treatment and financial issues [6, 7] These problems may have a large impact on the supportive care needs of ovarian cancer survivors. Supportive care can be defined as care that helps a person with cancer and his/her family to cope with the disease and treatment [7]. Several factors make ovarian cancer patients an at-risk group for high levels of unmet need, including female sex, more physical and psychological morbidities, having an advanced stage of disease at diagnosis and low income [6-8].

Adequate information provision is a frequently reported unmet supportive care need among gynecological cancer patients [2, 9, 10]. Among gynecological cancer patients, the likelihood of cure, information on the disease and its' spread and side effects of treatment are the most frequently mentioned information needs [10, 11]. Patients want to be informed, but information should be tailored to the patient's informational needs, literacy and personality [2, 12].

Patient information is an essential factor in support for cancer survivors [11]. Patients who reported satisfaction with the information received also reported better health-related quality of life, lower levels of distress and higher satisfaction with care [13]. Understanding factors associated with information provision may help health care providers provide more patient-centered information and reduce the number of unmet needs in survivorship [11, 13]. Prior research among breast, melanoma and prostate cancer survivors suggests that these patients have information needs in survivorship [16-18]. However, other studies have shown that the number of unmet needs decreases over time [14, 15] .

We hypothesize that ovarian cancer patients who are not satisfied with the perceived amount of information received during diagnosis and treatment have more unmet supportive care needs in survivorship. In this study, we examine the association between satisfaction with perceived level of received information during diagnosis and treatment in ovarian cancer survivors and their current supportive care needs. The aims of this study are (1) to measure

the past perceived level of and satisfaction with the amount of information received by ovarian cancer patients, (2) to measure the perceived (un)met supportive care needs of ovarian cancer patients, and (3) to correlate dissatisfaction with past perceived information provision with unmet supportive care needs after completing primary treatment.

METHODS

Setting and Participants

A cross-sectional study was conducted among women diagnosed with ovarian cancer between January 1st 2000 and July 1st 2010, as registered in the Netherlands Cancer Registry (NCR), in 6 hospitals in the southern region of the Netherlands. To be eligible, women must have been treated for ovarian cancer, have an adequate literacy level, speak and understand Dutch, have been treated in one of the affiliated hospitals and be alive at the time of the study. Vital status was established by the hospital patient file or by linking the NCR with the Central Bureau of Genealogy. Of 1147 registered women, 693 were identified as deceased according to the Central Bureau of Genealogy and 106 were identified as deceased, hospitalized or staying in a nursing home according to the hospital patient file. The remaining 348 received a questionnaire. The study was approved by a regional ethical committee (St. Elisabeth Hospital, no. 1149).

Procedures and data collection

All patients received an information letter from their gynecologist. Participating women completed the questionnaire after consenting to linking their questionnaire responses to NCR data. Data collection took place in 2012 and using PROFILES (Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship), a registry to study the physical and psychosocial impact of cancer and its treatment in a population-based cohort of cancer survivors (www.profilesregistry.nl). Details of the data collection method have been previously described [19].

Measures

Socio-demographic and clinical characteristics

Clinical and patient information were obtained from the NCR (i.e., date of birth, date of diagnosis, disease stage, and primary treatment) [20]. The questionnaire included questions on socio-demographic characteristics (i.e. marital status, employment status, and educational level). Co-morbidity at the time of survey was categorized according to the Self-administered Co-morbidity Questionnaire (SCQ) [21].

Information provision

To evaluate the perceived amount of information received during diagnosis and treatment (referred to as 'information provision') and satisfaction with the provided information among ovarian cancer survivors, the Dutch version of the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-INFO25 questionnaire was used [22]. This 25-item questionnaire incorporates four information provision subscales: perceived receipt of information about the disease (four items regarding diagnosis, spread of disease, cause(s) of disease and whether the disease is under control), medical tests (three items regarding purpose, procedures and results of tests), treatment (six items regarding medical treatment, benefits, side effects, effects on disease symptoms, social life and sexual activity) and other care services (four items regarding additional help, rehabilitation options, managing illness at home and psychological support). The question format is as follows: "during your current disease or treatment, how much information did you receive on . . .?" Additionally, the measure contains two single items on having received information and single items on the satisfaction with, amount of, and helpfulness of information. The answer categories are "not at all", "a little", "quite a bit", and "very much", except for four items which have a two point yes/no scale. Patients who reported being a little or not at all satisfied with the amount of information received were classified as not satisfied. Patients who reported being quite or very satisfied with the provided information were classified as satisfied with the information provision. After linear transformation, all scales and items range in scores from 0 to 100, with higher scores indicating better perceived information provision. The questionnaire has been internationally validated with good internal consistency for all scales ($\alpha > 0.70$), and good test-retest reliability (intraclass correlations > 0.70) [22]. Our data revealed Cronbach's alphas of 0.79 (disease), 0.90 (medical test), 0.88 (treatment) and 0.82 (other care services) for the four subscales respectively. The scale structure of the EORTC QLQ-INFO25 was recently validated [23].

Supportive care needs

Supportive care needs were measured using the Cancer Survivors' Unmet Needs measure (CaSUN), incorporating 35 questions on existential survivorship, comprehensive cancer care, information, quality of life and relationship domains. Respondents indicated whether each reported need had been met or unmet in the past month. The question format is as follows: "In the past month I need . . .?" (eg. "up to date information"). Participants answered 'No need', 'Met need' or 'Unmet need'. 'Unmet needs' were scored as weak, moderate or strong. From these scores, the number of met and unmet needs were calculated. The total number of needs is the sum of met and unmet needs coded as 1 when no need is coded as 0. The number of met needs is the sum of met needs coded as 1, when no need and unmet

need are coded as 0. The number of unmet needs is the sum of unmet needs coded as 1 when no need and met need are coded as 0. Higher scores indicate greater need (range 0-35) [8]. Our data revealed a Cronbach's alpha for the total CaSUN score of 0.93.

Statistical analysis

All statistical analyses were conducted using IBM SPSS Statistics version 22 (SPSS Inc., Chicago, IL, USA). P-values of <0.05 were considered statistically significant. Multi-items scales of the EORTC QLQ-INFO25 were only computed if at least half of the items from a scale were completed, according to the EORTC QLQ-C30 scoring guidelines [24]. For the CaSUN, missing items were counted as 'no need/not applicable' [16].

Frequencies and percentages were used to summarize categorical data. Means and standard deviations were used to summarize continuous data. Socio-demographic and clinical characteristics of respondents and non-respondents were compared using independent samples *t*-tests for continuous variables and chi-square tests for categorical variables. A chi-square test was used to evaluate the association between being satisfied or not satisfied with information provision and the number of unmet needs. T-test were used to compare mean information provision subscale scores of the QLQ-INFO25 in patients who were satisfied and patients who were not satisfied with information provision.

Multiple linear regression analyses were performed to evaluate the association between satisfaction with information provision (dichotomized item) and the number of unmet supportive care needs (dependent variable). A priori we included the treatment modality (surgery vs. surgery and chemotherapy), educational level (low vs. medium and low vs. high), marital status (partner yes vs. partner no), age at time of questionnaire completion, years since diagnosis and presence of co-morbidity (no vs. yes) as confounders, as previous studies have shown these factors are related to information provision [2]. As a sensitivity analysis, an interaction term was added to evaluate the relationship between satisfaction with information provision and time since diagnosis to assess whether the associations differ over time. Where the interaction was significant, we plotted simple slopes for -1 standard deviation (SD), the mean and $+1$ SD of time since diagnosis.

RESULTS

Patient characteristics

Of the 348 women who received a questionnaire, 191 responded (response rate of 55%). Six patients were excluded because more than half of their data were missing, resulting in 185 patients included in the analysis.

The mean age of respondents was 63 years (range 28 – 91 years), and the mean time since diagnosis was 6.2 years (range 1.9 – 12.3 years). Patients satisfied (65% of all respondents, n=120) with the amount of information provision were found to be more recently diagnosed than patients not satisfied with the information provision ($P=0.04$), but did not significantly differ in age, FIGO stage, treatment modality, employment or marital status (Table 1).

Information provision

Of 185 women, 15 (8%) were not at all, 50 (27%) a little, 71 (38%) quite a bit and 49 (27%) satisfied with the perceived amount of information received. Of all women, 120 (65%) were satisfied with the information provision and 65 (35%) were not satisfied with the information provision. Women satisfied with the information provision had significantly higher mean QLQ-INFO25 scales scores on all subscales than women not satisfied with information provision (Fig. 1A).

Supportive care needs

The five most frequently reported unmet needs are presented for patients satisfied and not satisfied with the information provision in Table 2. The 5 most frequently reported unmet needs for women satisfied and not satisfied with the information provision included 4 of the same needs: 'addressing of any complaints,' 'knowledge about intercollegial consultation between caregivers,' 'best medical care,' and 'access to complementary or alternative therapy services'. The two groups differed in that 'receiving information in an understandable way' fell in the top 5 unmet needs for women satisfied with the information provision, while 'access to health care services' fell in the top 5 unmet needs for women not satisfied with the information provision.

Association between satisfaction with information provision and unmet supportive care needs

Women who were satisfied with the amount of information provision reported fewer total (met and unmet) needs ($p=0.07$) and fewer unmet needs ($p=.02$; Table 1, Fig. 1B). After adjustment, women who were satisfied with the amount of information provision reported fewer unmet needs ($\beta=-2.66$, $p=0.03$; Table 3).

We found no evidence of interaction between satisfaction with the information provision and time since diagnosis ($\beta=0.20$, $p=0.61$).

DISCUSSION

More than one third of the ovarian cancer survivors were not satisfied with the perceived amount of information received. Patients who were not satisfied with the amount of information received, had more unmet supportive care needs. Important unmet needs of all patients included 'addressing of any complaints', 'knowledge about intercollegial consultation between caregivers', 'best medical care' and 'access to complementary or alternative therapy services'. Patients not satisfied with the information they received additionally reported 'Access to health care services when required' as an unmet need.

INFORMATION PROVISION

In previous studies, a majority of patients with various cancer types have reported not being satisfied with the amount of information they received (e.g. breast (36%), urological (34%), endometrial cancer (41%), melanoma (61%), lymphoma and multiple myeloma (33%)), similar to our study (45%) [10, 11, 25-27]. Patients not satisfied with the information provision reported lower scores on all subscales of provided information compared to satisfied patients. Further research is needed to understand why the patients were unsatisfied with the amount of information provided.

UNMET NEEDS

Our findings are comparable to those among other cancer types (breast, melanoma and prostate cancer) where patients reported similar percentages of unmet needs [16-18]. Patients reported needs concerning emotional and social support, management of healthcare and information [16-18]. The most frequently reported unmet supportive care needs among ovarian cancer survivors were addressing complaints, access to health care services, knowledge about intercollegial consultation between caregivers and best medical care. Other studies also found help with fear of cancer recurrence and worry about relatives as frequently reported unmet needs, however, these constructs were not measured in our study [16, 18].

ASSOCIATION BETWEEN SATISFACTION WITH INFORMATION PROVISION AND SUPPORTIVE CARE NEEDS

Patients not satisfied with the amount of information received, had more unmet supportive care needs compared to patients satisfied with the information provision. Patients also reported unmet needs not necessarily specific to information provision or medical care (e.g.

unmet needs in the domain of emotional issues or relationship concerns). These findings demonstrate the importance of providing sufficient information to ovarian cancer patients in order to address unmet needs in information provision and medical care as well as psychosocial domains for long-term survivors. Research among various tumor types shows that patients adequately informed according to their needs have better quality of life and less persisting unmet needs [10, 13]. Our results suggest that information provision meeting patient demands may help reduce unmet needs in survivorship. Adequate information provision may lead to fewer persisting unfulfilled needs overall by leaving fewer patients with unanswered questions and enabling patients to find supportive care services and the health care professional responsible for their care [10, 13].

CLINICAL IMPLICATIONS

It is important that information is tailored to the patient's needs [28]. During consultation the patient should regularly be asked if the information was understandable and helpful and whether personal needs have been met [29]. Providers can give more information to meet informational or medical care needs, and they can also meet needs in other domains too through appropriate referrals. By asking the patient, the health care provider can provide information according to the patients' needs at that specific point in their disease trajectory [30, 31].

During transition from patient to survivor, contact with the health care professional becomes less frequent and the patient is challenged to resume former roles while experiencing cancer related problems [32]. Care providers need to ensure sufficient information is provided during diagnosis, treatment, and after treatment has ended. Systematic screening, for example with the distress thermometer, may help the process more rigorous and consistent. Previous research has shown that provision of written information increases patients' satisfaction with perceived information [10]. One possible way to provide written information may be the implementation of survivorship care plans (SCPs). SCPs are one example of an effort to provide more detailed, tailored information to the patient to improve long-term survival and reduce unmet needs. SCPs are interventions containing written clinical information, such as diagnostic tests, type of cancer and treatment, and contact details of the caregivers responsible for their care [10, 33, 34]. SCPs contain a tailored follow-up care plan with information on possible short- and long-term effects, effects on social and sexual life, signs of recurrence and secondary tumors, and rehabilitation, psychosocial support and supportive care services [10, 33, 34]. Systematic reviews have shown that SCPs have a positive impact on reducing unmet needs during survivorship, and that breast cancer survivors were able to identify which caregiver was responsible for their care. However, the

reviews showed the SCPs have no significant effect on survivor distress, satisfaction with care, care coordination or oncological outcomes. [10, 33]. In addition, results of a SCP intervention for endometrial cancer and ovarian cancer survivors did not show improvement in satisfaction with information and care received, however, it did show a SCP may help empower patients [9, 35]. Additionally, SCPs were unable to enhance satisfaction with information provision or care in ovarian cancer survivors, possibly due to heightened concerns after receiving information about the chance of recurrence, it's treatment and prognosis[36]. Prior research revealed that this may be due to barriers in HCPs, as they are often reluctant to inform patients of a poor prognosis or provide information on late effects, and barriers in patients, such as personality and inhibition to ask for information.

STUDY LIMITATIONS

The strength of our study is the novelty it adds to the current literature. Only a few studies have investigated the relation between satisfaction with the amount of information provided and unmet supportive care needs among gynecological cancer patients [2, 9, 10]. Our study has several limitations. This cross-sectional study collected data with retrospective questions, resulting in recall bias (mean time since diagnosis was 6.2 years). Furthermore, selection bias may have occurred as we do not have detailed information about the health status of non-respondents (our response rate was 55%). However, previously we have shown that respondents and non-respondent have similar patient and tumor characteristics [37]. The results may also have been affected by survivorship bias due to low survival rates [38]. Of all selected patients, only 40% were still alive at the time of inclusion. In our study population 60% of women were diagnosed at an early stage of the disease, whilst 70% of all patients suffering from ovarian cancer are diagnosed with advanced disease [39]. Persistence of needs may be due to women experiencing one or more disease recurrences and receiving further chemotherapy (mean progression free survival after first line treatment varies between 10 and 19 months) [40, 41]. Unavailability of data on recurrent disease is a limitation of our study. Dissatisfaction with information may also indicate dissatisfaction in general. Personality affects illness perception and satisfaction with information provision [42]. This study relies on self-report measures of information provision, and it is not clear how much information was actually provided. Coping style of patients, could lead to underreporting of the received information [42]. Lastly, CaSUN is a generic questionnaire for assessing cancer patients' needs. For this reason, ovarian cancer survivors may not have had the opportunity to report their disease-specific needs [43].

CONCLUSION

It can be concluded that ovarian cancer survivors, dissatisfied with the information provision during and after their cancer treatment have more unmet supportive care needs in survivorship. Optimization of information provision by health care professionals during initial diagnosis and treatment may therefore contribute to a decrease in unmet needs during survivorship. Future research should assess manners to improve the information provision.

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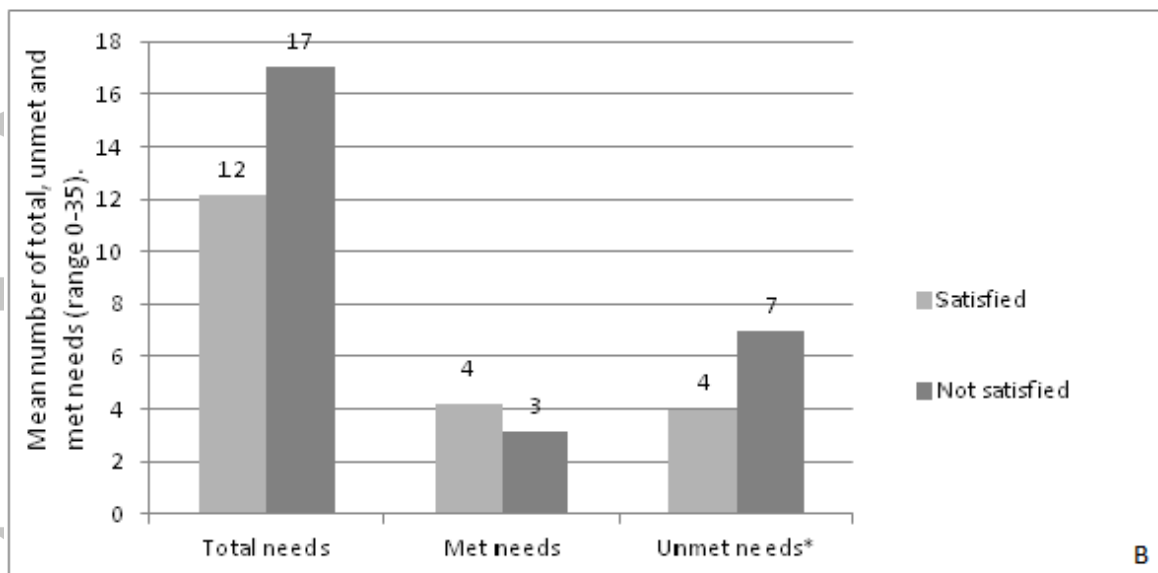
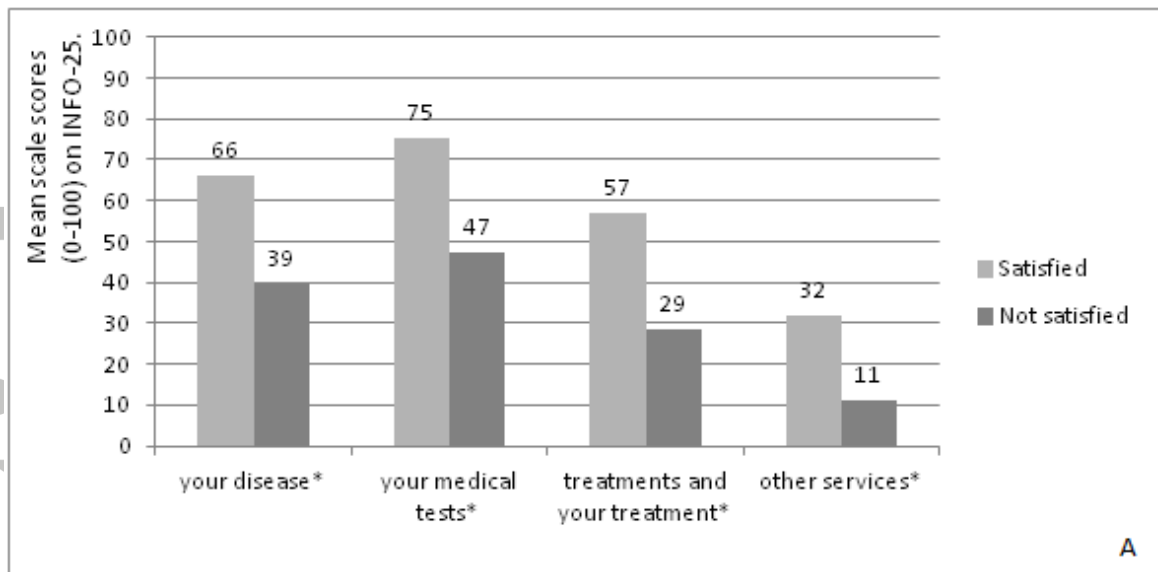


Fig 1A: Mean information provision scores on QLQ-INFO25 scales for patients who report being satisfied and not satisfied with the information provision (N=185)

* t-test, $p < 0.005$

Fig 1B: Association between satisfaction with information provision and mean scores for number of total, met and unmet needs (N=117)

* t-test, $p < 0.05$

Table 1: socio-demographic and clinical characteristics of ovarian cancer survivors, according to satisfaction with perceived information (N, %)

| | Satisfied patients (n=120) | Not satisfied patients (n=65) | p-value |
|---|---|---|---------|
| Age at time of survey years mean, (SD) range | 63.5 (11.1) 39 – 88 | 63.3 (11.9) 28 – 91 | NS |
| Years since diagnosis years mean, (SD) range | 5.8 (3.0) 1.9 – 12.3 | 6.9 (3.2) 1.9 – 12.2 | 0.04 |
| FIGO stage at diagnosis (n, %) | | | NS |
| I | 71 (59) | 41 (63) | |
| II | 14 (12) | 6 (9) | |
| III | 26 (22) | 17 (26) | |
| IV | 8 (7) | 0 (0) | |
| unknown | 1 (1) | 1 (2) | |
| Treatment (n, %) | | | NS |
| Surgery | 35 (29) | 22 (34) | |
| Surgery+ CTx | 83 (69) | 42 (65) | |
| CTx | 1 (1) | 0 (0) | |
| Other | 1 (1) | 1 (2) | |
| Co-morbidities (n, %) | | | NS |
| Yes | 84 (70) | 42 (65) | |
| no | 36 (30) | 23 (35) | |
| Most frequent comorbidity (n,%) | Arthritis 44 (24) Backache 36 (19) Hypertension 32 (17) | Liver disease 49 (26) Ulcer 48 (26) Arthritis 25 (14) | NS |
| Socio-economic status (n, %) | | | NS |
| High | 42 (35) | 15 (23) | |
| Middle | 52 (43) | 27 (42) | |
| Low | 22 (18) | 21 (32) | |
| Missing | 4 (3) | 2 (3) | |
| Educational level (n, %) | | | NS |
| High | 22 (18) | 11 (17) | |
| Medium | 73 (61) | 43 (66) | |
| Low | 20 (17) | 10 (15) | |
| Missing | 5 (4) | 1 (2) | |
| Employed (n, %) | | | NS |
| Yes | 26 (21) | 17 (28) | |
| No | 81 (68) | 44 (68) | |
| Missing | 12 (10) | 4 (6) | |
| Marital status at time of survey(n, %) | | | NS |
| Partner | 79 (66) | 41 (63) | |
| No partner | 38 (32) | 23 (35) | |
| Missing | 3 (3) | 1 (2) | |
| Marital status at time of diagnosis(n, %) | | | NS |
| Partner | 75 (63) | 39 (60) | |
| No partner | 7 (6) | 5 (8) | |
| Missing | 38 (32) | 21 (32) | |
| Mean total CASUN score (SD)* | 12.2 (12.1) | 13.9 (14.1) | NS |
| Mean CASUN score | 4.0 (5.7) | 6.3 (6.9) | 0.02 |

| | | | |
|-------------------------------------|-----------|-----------|----|
| unmet needs (SD)* | | | |
| Mean CASUN score met needs (SD)* | 4.2 (5.3) | 3.2 (6.3) | NS |

T-test was performed for continuous variables and Chi square test for dichotomous; NS: not significant; SD: standard deviation; CTx: chemotherapy; *scores can range from 0 to 35.

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Table 2: five most frequently reported unmet needs of satisfied and not satisfied patients

| CASUN needs description Need for... | Not satisfied patients % (n reporting unmet need/completing item) | Satisfied patients % (n reporting unmet need/completing item) |
|--|---|---|
| Addressing of any complaints | 61 (35/57) | 26 (31/99) |
| Knowledge about intercollegial consultation between caregivers | 52 (29/56) | 24 (29/101) |
| Access to health care services when required | 47 (26/55) | NA |
| Best medical care | 43 (22/51) | 19 (23/99) |
| Access to complementary or alternative therapy services | 34 (21/61) | 27 (32/94) |
| Information provided in a understandable way | NA | 11 (13/105) |

NA= not applicable. i.e. unmet need, not reported as one of the five most frequently reported unmet needs.

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Table 3: multivariable linear regression analysis evaluating the association of satisfaction with perceived amount of information with unmet needs. (N=117)

| | Unmet needs (β) | 95% CI |
|--|-------------------------|----------------|
| Satisfaction with perceived amount of information received | | |
| Satisfied vs. not satisfied (ref) | -2.7* | [-5.1 ; -0.3] |
| Treatment | | |
| Surgery and chemotherapy vs. surgery (ref) | 3.1* | [0.5 ; 5.7] |
| Educational level | | |
| Low (ref) vs. medium | 3.1 | [-0.2 ; 6.5] |
| Low (ref) vs. high | 1.6 | [-2.4 ; 5.5] |
| Partner | | |
| No vs. yes (ref) | 1.6 | [-0.9 ; 4.1] |
| Age at time of questionnaire | -0.2** | [-0.3 ; 0.0] |
| Years since diagnosis | -0.3 | [-0.7 ; 0.1] |
| Comorbidity | | |
| Yes vs. no (ref) | 1.3** | [0.6 ; 2.1] |

* p<0.05

** p<0.01

ref: reference category; β = unstandardized beta coefficient CI: confidence interval. Analyses were adjusted for the following confounders: treatment modality (surgery vs. surgery and chemotherapy), educational level (low vs. medium and low vs. high), marital status (partner yes vs. partner no), age at time of questionnaire completion, years since diagnosis and presence of co-morbidity (no vs. yes).