# Current organisation of follow-up does not meet cancer patients' needs 

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#### Abstract

INTRODUCTION: For cancer patients, traditional follow-up care is considered unsuitable and unsustainable. The patient perspective seems often to be absent in the ongoing debate about alternative strategies for follow-up care. Based on a national survey from 2012, the objective of this study was to examine cancer patients' support needs regarding physiological and emotional problems during fol-low-up and to identify factors associated with their needs and any unmet needs. MATERIAL AND METHODS: Patients diagnosed with cancer in the period from April to September 2010 were invited to participate. A total of 4,401 patients responded (response rate $=64 \%$ ). The risks in terms of prevalence rate ratios of having needs and unmet needs for both physiological and emotional problems were estimated using the Poisson regression. RESULTS: The study showed that $60 \%$ of the patients had needs for support regarding physiological and emotional problems, and half of the patients reported unmet needs. Younger patients and patients with co-morbidity were more likely to report needs and unmet needs for physiological and emotional support. Treatment complexity and setting of follow-up were not associated with unmet needs. CONCLUSION: The study underlines that the current organisation of follow-up does not meet cancer patients' needs. Several factors are associated with both needs and unmet needs. Hence, a more sustainable approach for follow-up care may consist in stratification tailored to the patients' different needs. In such an approach, more focus should be on age-specific needs and the impact of co-morbidity. FUNDING: The study is funded by the Danish Cancer Society. TRIAL REGISTRATION: The study was approved by the Danish Data Protection Agency (J. no. 2010-41-4694). According to the Danish Act on Research Ethics Review of Health Research Projects (S. 8(3) of Act No. 402 of 28 May 2003), no ethical approval was needed.


Every year, 36,000 new cancer cases are diagnosed in Denmark, and more than 245,000 persons were alive with a cancer diagnosis in 2011 [1]. Most cancer patients are referred to follow-up care after completing their initial treatment. The follow-up usually involves outpatient check-ups with the primary aim of checking for recur-
rence or metastasis and the secondary aim of providing information and psychosocial support [2].

The effect of follow-up on survival remains questionable [3, 4], and it has been shown that traditional follow-up does not meet the patients' needs $[5,6]$. Furthermore, as the number of people diagnosed with cancer will increase tremendously in the future, pressure on the resource allocation for the traditional fol-low-up care is expected. Alternative strategies for fol-low-up care have been widely discussed in a national and international context. Such potential strategies have included patient-initiated follow-up [7], nurse-led fol-low-up [8] and primary care involvement [9, 10]. In Denmark, the Ministry of Health has required a modernisation of the current organisation of follow-up care, which will be carried out by disease-specific workgroups in 2013 and 2014.

From the patients' perspective, check for recurrence seems to be the most important aspect of follow-up care, but the management of late effects and the provision of psychosocial support are also important aspects for the patients [5, 11]. However, little is known about the patients' perspective on their needs and unmet needs during follow-up. The patients are the best and only reliable reporters regarding their needs and experiences, and they serve as an important source of information about the quality of health care. However, the patient's perspective often seems to be absent in the ongoing debate about alternative strategies for follow-up care.

To obtain a better understanding of the factors that predict needs and unmet needs among cancer patients, the Danish Cancer Society conducted a national survey in 2012 inviting almost 7,000 patients to give their perspective on the care delivered during and after the treatment [12]. In the survey, the patients' needs for support during follow-up care were addressed.

Based on the national survey, the objective of this study was to examine cancer patients' needs for support regarding physiological and emotional problems during follow-up and to identify which factors were associated with needs and unmet needs.

## MATERIAL AND METHODS

The study was a population-based, nationwide crosssectional study.

## ORIGINAL

## ARTICLE

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Follow-up in Danish health care. (Foto: Bigstock).

## Setting

The study took place in 2012 in Denmark. The publicly funded Danish health-care system ensures free access to diagnostics and treatment for all citizens.

## Study population

The study population consisted of all patients aged 18 years or older who were diagnosed with an incident cancer diagnosis coded as C00.0-C99.9 (except for C44.*) according to the International Classification of Diseases (10th Edition) during the period from 16 April to 15 September 2010 and who were alive by 4 June 2012 (7,615 patients). A total of 701 ( $9.2 \%$ ) patients were excluded due to a standing rejection by the respondents to be contacted for research purposes, including unknown status (89 patients). In total, 6,914 patients were included in the study.

The patients were identified in the Danish National Patient Register (NPR) [13]. Patients were eligible for inclusion if they were registered with cancer as their primary diagnosis and had no prior history of cancer. The latter was checked using the Danish Cancer Registry (DCR) [14].

## FIGURE 1

Categorisation of items of interest.


## Data collection

A questionnaire, including a prepaid envelope, was sent to each patient. After three weeks, non-responders were sent a reminder, including a new questionnaire.

The primary aim of the survey was to examine Danish cancer patients' experiences with health-care services during and after their initial cancer treatment. A review of the literature and several focus group interviews were conducted to identify substantial needs and problems for cancer patients. A questionnaire was developed containing 121 items addressing the patient's pathway during treatment and survivorship. The validity was pilot-tested through qualitative interviews with cancer patients who differed with regard to age, gender and diseases. The questionnaire was also validated by professionals from both clinical and research settings.

## Variables

The variables of interest to this study were whether the patients had experienced a need for physiological or emotional support (needs) and whether the patients had experienced that their needs were not met during follow-up care (unmet needs). The categorisation of the items into needs and unmet needs is illustrated in Figure 1.

Other variables were gender; age; cohabitant status; cancer type and comorbidity; if the patient received surgery, chemotheraphy or radiotherapy; treatment complexity (surgery and/or chemotherapy and/or radiotherapy); and the follow-up setting. Gender, age, cohabitant status and cancer type were register-based information. The remaining variables were patientreported. Comorbidity was defined as the presence of one or more chronic diseases in addition to the primary cancer diagnosis and was gathered through a combination of closed and open items.

## Data analyses

Key patient characteristics for responders and non-responders were compared using non-parametric tests. The analyses of needs and unmet needs were restricted to patients who reported that they had been to a followup visit ( $n=4,159$ ).

The likelihood of having needs or unmet needs for both physiological and emotional problems was estimated using prevalence rate ratios based on a Poisson distribution, which facilitates direct estimation of prevalence ratios without the risk of overestimating the risk [15]. The multivariate model included all the variables that had a p-value below 0.1 in the univariate models. Results are presented with $95 \%$ confidence intervals (CI) where relevant. Analyses were performed using Stata v. 11.2 (StataCorp, College Station, Texas).

Trial registration: The study was approved by the Danish Data Protection Agency (J. no. 2010-41-4694). According to the Danish Act on Research Ethics Review of Health Research Projects (S. 8(3) of Act No. 402 of 28 May 2003), no ethical approval was needed.

## RESULTS

Of the 6,914 questionnaires mailed, a total of 4,401 (63.7\%) were returned. Responders were more likely to be women and patients diagnosed with malignant melanoma. Non-responders were more likely to be younger than 40 years old, older than 70 years, single or diagnosed with "rare cancers" (Table 1). Of all patients, $94.1 \%$ continued with follow-up care after treatment, and $92.3 \%$ of these services were rendered at a hospital.

Overall, 63.2\% reported needs for support regarding physiological problems, and $58.6 \%$ reported having needs for support regarding emotional problems. Unmet needs were reported in relation to physiological problems by $51.6 \%$ and in relation to emotional problems by 61.1\% of the patients (Table 2 and Table 3).

## Factors associated with the patients' needs

Patients with co-morbidity and patients receiving chemotherapy were more likely to report a need for support regarding physiological problems. Also, patients reported a higher need for support if they were younger than 60 years of age or were diagnosed with breast cancer, lymphoma or rare cancers. In contrast, patients with malignant melanoma were less likely to report a need (Table 2).

Younger patients were more likely than patients over 70 years to have a need for support regarding emotional problems. Furthermore, females, patients with comorbidity and patients receiving chemotherapy were more likely to report a need. Malignant melanoma was associated with a lower risk of reporting a need for emotional support (Table 3).

## Factors associated with unmet needs

Patients younger than 60 years of age, patients with comorbidity, and females had a higher risk for reporting unmet needs for physiological problems, whereas patients diagnosed with breast cancer, lymphoma, or malignant melanoma had a lower risk. Age and co-morbidity showed the strongest associations (Table 2).

## Patients with co-morbidity and patients younger

 than 50 years had the strongest associations with unmet needs for emotional problems. Also, females and singles had a slightly higher risk. Patients with gastrointestinal, prostate or lung cancer had the highest risk of unmet needs for emotional support, whereas patients diagnosed with gynaecological cancers had a lower risk (Table 3).
## DISCUSSION

The patient perspective on follow-up care among a group of patients diagnosed with a cancer diagnosis approximately two years ago was addressed.

The results showed that approximately $60 \%$ of the cancer patients reported needs for either physiological or emotional support. Hence, a significant group of patients reported no need for support. This illustrates the diversity in cancer patients' needs post treatment; some patients are able to return to a normal and healthy life without professional help, but others struggle with emotional problems and late effects.

Furthermore, among the patients having needs for support, more than half reported unmet needs. That the current follow-up care does not meet cancer patients' physical and psychosocial needs is also reported in other studies [5, 6].

Patients with co-morbidity and younger patients were found to be more likely to experience needs for both physiological and emotional support, and more likely to report unmet needs. This was also found in a Norwegian study where cancer patients with co-morbidity generally had greater needs for physical and psychosocial rehabilitation and more frequently experienced that their needs were unmet [16]. However, the evi-

## TABLE 1

Response analysis by patient characteristics. Frequencies shown for total population, non-responders and responders ( $\mathrm{N}=4,401$ ).

|  | Population, n (\%) | Respondent, n (\%) | Non-respondents, n (\%) | Test of difference, p-value ${ }^{\text {a }}$ |
| :---: | :---: | :---: | :---: | :---: |
| Total | - | 4,401 (63.7) | 2,513 (36.4) | - |
| Sex |  |  |  | < 0.001 |
| Male | 3,441 (49.8) | 2,119 (48.2) | 1,322 (52.6) |  |
| Female | 3,473 (50.2) | 2,282 (51.9) | 1,191 (47.4) |  |
| Age, yrs |  |  |  | < 0.001 |
| 18-39 | 357 (5.2) | 169 (3.8) | 188 (7.5) |  |
| 40-49 | 598 (8.7) | 368 (8.4) | 230 (9.2) |  |
| 50-59 | 1,306 (18.9) | 859(19.5) | 447 (17.8) |  |
| 60-69 | 2,339 (33.8) | 1,611(36.6) | 728 (29.0) |  |
| $\geq 70$ | 2,314 (33.5) | 1,394 (31.7) | 920 (36.6) |  |
| Cohabitation status |  |  |  | < 0.001 |
| Widow/widower | 1,067 (15.4) | 584 (13.3) | 483 (19.2) |  |
| Single | 1,547 (22.4) | 856 (19.5) | 691 (27.5) |  |
| Married/living together | 4,300 (62.2) | 2,961 (67.3) | 1,339 (53.3) |  |
| Cancer type |  |  |  | $<0.001$ |
| Breast | 1,120 (25.4) | 177 (60.0) | 118 (40.0) |  |
| Prostate | 853 (19.4) | 735 (60.1) | 233 (39.9) |  |
| Gastrointestinal | 735 (16.7) | 190 (58.8) | 133 (41.2) |  |
| Lymphoma and blood | 336 (7.6) | 285 (61.3) | 180 (38.7) |  |
| Melanoma | 285 (6.5) | 1,120 (72.9) | 417 (27.1) |  |
| Gynaecological | 237 (5.4) | 243 (58.1) | 77 (41.9) |  |
| Urinary tract | 211 (4.8) | 853 (66.3) | 433 (33.7) |  |
| Lung | 190 (4.3) | 211 (61.7) | 131 (38.3) |  |
| Head and neck | 177 (4.0) | 343 (59.6) | 233 (40.5) |  |
| Rare cancers | 257 (5.8) | 220 (49.8) | 222 (50.2) |  |

a) $\chi^{2}$-test.
dence on how co-morbidities influence cancer patients' lives after treatment remains sparse.

With regard to age, studies have shown that young adults diagnosed with cancer meet challenges that are different from those experienced by older patients [17,

18], and that the unique needs of younger patients require an age-specific infrastructure of follow-up care [18]. This could explain why the young patients in our study were more likely to report needs and unmet needs in the follow-up care.

## 國 TABLE 2

Frequencies and prevalence rate ratios for the patients' needs and unmet needs in regard to physiological problems.

|  | Needs for physiological problems |  |  | Unmet needs for physiological problems |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | n (\%) | PRR unadjusted ( $95 \% \mathrm{Cl}$ ) | PRR adjusted ${ }^{\text {a }}$ <br> (95\% CI) | n (\%) | PRR unadjusted (95\% CI) | PRR adjusted $^{\text {a }}$ ( $95 \% \mathrm{Cl}$ ) |
| Total | 2,380 (63.2) | - | - | 1,229 (51.6) | - | - |
| Sex <br> Male <br> Female | $\begin{aligned} & 1,047(59.8) \\ & 1,333(66.2) \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.11 \text { (1.05-1.16) } \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 0.97 \text { (0.90-1.04) } \end{aligned}$ | $\begin{aligned} & 514 \text { (49.1) } \\ & 715 \text { (53.6) } \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.09 \text { (1.01-1.18) } \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.12 \text { (1.0-1.26) } \end{aligned}$ |
| Age, yrs <br> 18-39 <br> 40-49 <br> 50-59 <br> 60-69 <br> $\geq 70$ | $\begin{array}{r} 94 \text { (63.5) } \\ 221 \text { (72.9) } \\ 532(71.7) \\ 902(62.7) \\ 631(55.6) \end{array}$ | $\begin{aligned} & 1.14(1.00-1.30) \\ & 1.31(1.20-1.43) \\ & 1.29(1.20-1.38) \\ & 1.13(1.06-1.20) \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.18 \text { (1.04-1.35) } \\ & 1.20 \text { (1.09-1.33) } \\ & 1.19 \text { (1.10-1.29) } \\ & 1.10 \text { (1.02-1.18) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{array}{r} 58 \text { (61.7) } \\ 136 \text { (61.5) } \\ 303 \text { (57.0) } \\ 436 \text { (48.3) } \\ 296 \text { (46.9) } \end{array}$ | $\begin{aligned} & 1.32(1.10-1.57) \\ & 1.31(1.15-1.36) \\ & 1.21(1.09-1.37) \\ & 1.03 \text { (0.93-1.15) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.43 \text { (1.17-1.74) } \\ & 1.37(1.17-1.61) \\ & 1.26(1.11-1.43) \\ & 1.06 \text { (0.95-1.20) } \\ & 1 \text { (ref) } \end{aligned}$ |
| Cohabitation status <br> Widow/widower <br> Single <br> Married/living together | $\begin{array}{r} 273(59.6) \\ 505(67.8) \\ 1,602(62.5) \end{array}$ | $\begin{aligned} & 0.95 \text { (0.88-1.03) } \\ & 1.08 \text { (1.02-1.15) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.04 \text { (0.95-1.14) } \\ & 1.04 \text { (0.98-1.11) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 132(48.4) \\ & 288(57.0) \\ & 809(50.5) \end{aligned}$ | $\begin{aligned} & 0.96 \text { (0.84-1.09) } \\ & 1.12(1.03-1.24) \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.03 \text { (0.89-1.20) } \\ & 1.06 \text { (0.96-1.16) } \\ & 1 \text { (ref) } \end{aligned}$ |
| Cancer type <br> Breast <br> Prostate <br> Gastrointestinal <br> Lymphoma and blood <br> Melanoma <br> Gynaecological <br> Urinary tract <br> Lung <br> Head and neck <br> Rare cancers | $\begin{aligned} & 750(71.8) \\ & 362(55.5) \\ & 352(59.5) \\ & 196(71.3) \\ & 104(39.5) \\ & 138(65.7) \\ & 103(57.9) \\ & 113(69.3) \\ & 104(63.8) \\ & 158(70.5) \end{aligned}$ | $\begin{aligned} & 1.21(1.12-1.30) \\ & 0.93 \text { (0.85-1.03) } \\ & 1 \text { (ref) } \\ & 1.20(1.08-1.33) \\ & 0.67(0.56-0.78) \\ & 1.11(0.98-1.24) \\ & 0.97(0.84-1.12) \\ & 1.17(1.03-1.32) \\ & 1.07(0.9-1.23) \\ & 1.19(1.07-1.32) \end{aligned}$ | $\begin{aligned} & 1.13 \text { (1.02-1.24) } \\ & 1.05 \text { (0.93-1.18) } \\ & 1 \text { (ref) } \\ & 1.15 \text { (1.02-1.29) } \\ & 0.73 \text { (0.61-0.87) } \\ & 1.18 \text { (1.03-1.34) } \\ & 1.05 \text { (0.90-1.21) } \\ & 1.08 \text { (0.95-1.23) } \\ & 1.08 \text { (0.94-1.24) } \\ & 1.15 \text { (1.02-1.29) } \end{aligned}$ | $\begin{array}{r} 400(53.3) \\ 177(48.9) \\ 206(58.5) \\ 85(43.4) \\ 50(48.1) \\ 59(42.8) \\ 50(48.5) \\ 59(52.2) \\ 53(51.0) \\ 90(57.0) \end{array}$ | 0.91 (0.82-1.02) 0.84 (0.73-0.96) 1 (ref) $0.74(0.62-0.89)$ $0.82(0.66-1.02)$ 0.73 (0.59-0.90) $0.82(0.67-1.03)$ $0.89(0.73-1.09)$ $0.87(0.71-1.07)$ $0.97(0.83-1.14)$ | $\begin{aligned} & 0.78 \text { (0.68-0.90) } \\ & 0.89 \text { (0.76-1.06) } \\ & 1 \text { (ref) } \\ & 0.69 \text { (0.57-0.84) } \\ & 0.79(0.62-1.00) \\ & 0.68(0.55-0.86) \\ & 0.86(0.67-1.08) \\ & 0.84(0.69-1.03) \\ & 0.82(0.66-1.02) \\ & 0.88(0.74-1.05) \end{aligned}$ |
| Co-morbidity Yes <br> No | $\begin{aligned} & 1,008(71.0) \\ & 1,173(57.1) \end{aligned}$ | $\begin{aligned} & 1.24 \text { (1.18-0.31) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.23 \text { (1.17-1.30) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 598(59.3) \\ & 530(45.2) \end{aligned}$ | $\begin{aligned} & 1.31 \text { (1.21-1.42) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.33 \text { (1.23-1.44) } \\ & 1 \text { (ref) } \end{aligned}$ |
| Surgery Yes No | $\begin{array}{r} 1,838 \text { (63.1) } \\ 542(63.5) \end{array}$ | $\begin{aligned} & 0.99 \text { (0.94-1.05) } \\ & 1 \text { (ref) } \end{aligned}$ | Not included | $\begin{aligned} & 966(52.6) \\ & 263(48.5) \end{aligned}$ | $\begin{aligned} & 1.08 \text { (0.98-1.19) } \\ & 1 \text { (ref) } \end{aligned}$ | Not included |
| Radiotherapy <br> Yes <br> No | $\begin{aligned} & 1,076 \text { (72.4) } \\ & 1,304(57.2) \end{aligned}$ | $\begin{aligned} & 1.26 \text { (1.21-1.33) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.09 \text { (1.00-1.19) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 575 \text { (53.4) } \\ & 654 \text { (50.2) } \end{aligned}$ | $\begin{aligned} & 1.07 \text { (0.99-1.15) } \\ & 1 \text { (ref) } \end{aligned}$ | Not included |
| Chemotherapy Yes No | $\begin{array}{r} 973 \text { (76.9) } \\ 1,407(56.3) \end{array}$ | $\begin{aligned} & 1.37 \text { (1.30-1.43) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.22 \text { (1.11-1.33) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 694 \text { (49.3) } \\ & 535 \text { (55.0) } \end{aligned}$ | $\begin{aligned} & 1.11(1.03-1.20) \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.02 \text { (0.89-1.16) } \\ & 1 \text { (ref) } \end{aligned}$ |
| Treatment complexity <br> 1 type of treatment <br> 2 types of treatments <br> 3 types of treatments <br> No treatment | $\begin{aligned} & 996(48.8) \\ & 793(56.9) \\ & 435(68.0) \\ & 156(82.5) \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.20 \text { (1.13-1.27) } \\ & 1.45 \text { (1.37-1.54) } \\ & 0.86(0.76-0.97) \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 0.98 \text { (0.89-1.07) } \\ & 1.01 \text { (0.86-1.18) } \\ & 0.88 \text { (0.77-1.01) } \end{aligned}$ | $\begin{gathered} 480(48.2) \\ 423(53.3) \\ 250(57.5) \\ 76(48.7) \end{gathered}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.11 \text { (1.01-1.21) } \\ & 1.19 \text { (1.08-1.32) } \\ & 1.01 \text { (0.85-1.20) } \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.07 \text { (0.94-1.21) } \\ & 1.06 \text { (0.88-1.27) } \\ & 1.10 \text { (0.91-1.33) } \end{aligned}$ |
| Setting for follow-up <br> At hospital by a doctor <br> At hospital by a nurse <br> At hospital by a nurse and a doctor <br> At specialist practice <br> At general practice <br> Other places <br> More places | $\begin{array}{r} 1,828 \text { (63.3) } \\ 85(59.4) \\ 258(68.3) \\ 7(30.4) \\ 19(51.4) \\ 12(50.0) \\ 133(62.4) \end{array}$ | 1 (ref) <br> 0.93 (0.81-1.07) <br> 1.07 (1.00-1.16) <br> 0.48 (0.26-0.89) <br> 0.81 (0.59-1.11) <br> 0.79 (0.53-1.17) <br> 0.98 (0.88-1.09) | $\begin{aligned} & 1 \text { (ref) } \\ & 1.07 \text { (0.93-1.22) } \\ & 1.07 \text { (0.99-1.15) } \\ & 0.52 \text { (0.29-0.94) } \\ & 0.94(0.66-1.34) \\ & 0.81 \text { (0.54-1.20) } \\ & 1.07 \text { (0.95-1.19) } \end{aligned}$ | $\begin{array}{r} 959(52.5) \\ 44(51.8) \\ 130(50.4) \\ 2(28.6) \\ 9(47.4) \\ 8(66.7) \\ 75(43.6) \end{array}$ | 1 (ref) <br> 0.99 (0.80-0.21) <br> 0.96 (0.84-1.09) <br> 0.54 (0.17-1.76) <br> 0.90 (0.56-1.45) <br> 1.27 (0.85-1.90) <br> 0.83 (0.68-1.01) | Not included |

$\mathrm{Cl}=$ confidence interval; $\mathrm{PRR}=$ prevalence rate ratio; ref = reference group.
a) adjusted for the covariates with a $p$ value below 0.1 in the univariate analyses.

No specific cancer diseases turned out with a consistent positive or negative result for both needs and unmet needs. However, cancer disease seemed to have greater impact on the physiological dimension than on the emotional dimension. Furthermore, for some cancer
types (eg. breast and gynaeological cancer), a high level of needs for physiological support was associated with a low level of unmet needs; however, for other cancer types (e.g colorectal and urinary tract cancer), we found a high level of unmet needs despite a low prevalence of

## TABLE 3

Univariate and multivariate analyses for the patients' needs and unmet needs regard to emotional problems.

|  | Needs for emotional problems |  |  | Unmet needs for emotional problems |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | n (\%) | PRR unadjsuted (95\% CI) | PRR adjusted $^{\text {a }}$ (95\% CI) | n (\%) | PRR unadjusted (95\% CI) | PRR adjusted $^{\text {a }}$ (95\% CI) |
| Total | 2,136 (58.6) | - | - | 1,305 (61.1) | - | - |
| Sex <br> Male <br> Female | $\begin{array}{r} 911 \text { (54.7) } \\ 1,225(61.9) \end{array}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.13 \text { (1.07-1.20) } \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.13 \text { (1.04-1.23) } \end{aligned}$ | $\begin{aligned} & 534 \text { (58.6) } \\ & 771 \text { (62.9) } \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.07 \text { (1.00-1.15) } \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.11 \text { (1.01-1.22) } \end{aligned}$ |
| Age, yrs <br> 18-39 <br> 40-49 <br> 50-59 <br> 60-69 <br> $\geq 70$ | $\begin{array}{r} 99(67.4) \\ 222(73.0) \\ 502(67.6) \\ 781(55.6) \\ 532(50.9) \end{array}$ | $\begin{aligned} & 1.32 \text { (1.17-1.50) } \\ & 1.44 \text { (1.31-1.57) } \\ & 1.33 \text { (1.23-1.44) } \\ & 1.09 \text { (1.01-1.18) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.38(1.20-1.59) \\ & 1.40 \text { (1.26-1.55) } \\ & 1.27(1.16-1.39) \\ & 1.09(1.00-1.18) \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{array}{r} 84(84.9) \\ 156(70.3) \\ 312(62.2) \\ 433(55.4) \\ 320(60.2) \end{array}$ | $\begin{aligned} & 1.41 \text { (1.27-1.57) } \\ & 1.16(1.05-1.30) \\ & 1.03 \text { (0.94-1.14) } \\ & 0.92 \text { (0.84-1.01) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.41(1.24-1.62) \\ & 1.17(1.03-1.34) \\ & 1.04(0.93-1.16) \\ & 0.94(0.84-1.04) \\ & 1 \text { (ref) } \end{aligned}$ |
| Cohabitation status <br> Widow/widower <br> Single <br> Married/living together | $\begin{array}{r} 232(54.7) \\ 461(63.3) \\ 1,143(57.9) \end{array}$ | $\begin{aligned} & 0.95 \text { (0.86-1.04) } \\ & 1.09 \text { (1.02-1.17) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.01 \text { (0.90-1.12) } \\ & 1.02 \text { (0.95-1.09) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 136(58.6) \\ & 319 \text { (69.2) } \\ & 850(58.9) \end{aligned}$ | $\begin{aligned} & 1.00(0.86-1.12) \\ & 1.17 \text { (1.09-0.27) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.00 \text { (0.88-1.15) } \\ & 1.11(1.03-1.20) \\ & 1 \text { (ref) } \end{aligned}$ |
| Cancer type <br> Breast <br> Prostate <br> Gastrointestinal <br> Lymphoma and blood <br> Melanoma <br> Gynaecological <br> Urinary tract <br> Lung <br> Head and neck <br> Rare cancers | $\begin{array}{r} 637 \text { (62.3) } \\ 324 \text { (52.9) } \\ 328(56.9) \\ 177(65.1) \\ 122(47.5) \\ 121(59.0) \\ 97(55.1) \\ 93(62.0) \\ 105(65.2) \\ 132(62.3) \end{array}$ | $1.10(1.00-1.19)$ 0.93 (0.84-1.03) 1 (ref) $1.14(1.02-1.28)$ $0.84(0.72-0.97)$ $1.04(0.91-1.19)$ $0.97(0.83-1.13)$ $1.09(0.94-1.26)$ $1.15(1.00-1.31)$ $1.10(0.97-1.24)$ | 0.93 (0.84-1.04) 1.08 (0.95-1.22) 1 (ref) 1.07 (0.94-1.21) 0.83 (0.70-0.97) $0.97(0.83-1.12)$ $1.02(0.87-1.18)$ 1.01 (0.87-1.18) 1.15 (0.99-1.32) 1.04 (0.91-1.19) | $\begin{array}{r} 395(62.0) \\ 183(56.5) \\ 212(64.6) \\ 103(58.2) \\ 80(65.6) \\ 60(49.6) \\ 63(65.0) \\ 59(63.4) \\ 64(61.0) \\ 86(65.2) \end{array}$ | $\begin{aligned} & 0.96 \text { (0.87-1.06) } \\ & 0.87 \text { (0.77-0.99) } \\ & 1 \text { (ref) } \\ & 0.90 \text { (0.78-1.04) } \\ & 1.01 \text { (0.87-1.18) } \\ & 0.77 \text { (0.63-0.93) } \\ & 1.00(0.85-1.19) \\ & 0.98(0.82-1.68) \\ & 0.94 \text { (0.79-1.12) } \\ & 1.01 \text { (0.87-1.17) } \end{aligned}$ | 0.89 (0.79-1.00) 0.96 (0.83-1.12) 1 (ref) $0.86(0.74-1.00$ $0.93(0.78-1.10)$ $0.72(0.59-0.89)$ $1.10(0.92-1.31)$ $0.95(0.80-1.13)$ $0.93(0.78-1.10)$ $0.93(0.79-1.09)$ |
| Co-morbidity Yes <br> No | $\begin{array}{r} 905(65.8) \\ 1,051(52.6) \end{array}$ | $\begin{aligned} & 1.25 \text { (1.18-1.32) } \\ & 1 \end{aligned}$ | $\begin{aligned} & 1.26 \text { (1.19-1.34) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 619 \text { (68.4) } \\ & 579(55.1) \end{aligned}$ | $\begin{aligned} & 1.24 \text { (1.16-1.33) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.25 \text { (1.17-1.34) } \\ & 1 \text { (ref) } \end{aligned}$ |
| Surgery Yes No | $\begin{array}{r} 1,661(51.5) \\ 475(47.4) \end{array}$ | $\begin{aligned} & 0.98 \text { (0.92-1.04) } \\ & 1 \text { (ref) } \end{aligned}$ | Not included | $\begin{array}{r} 1,006 \text { (60.6) } \\ 299(63.0) \end{array}$ | $\begin{aligned} & 0.96 \text { (0.98-1.19) } \\ & 1 \text { (ref) } \end{aligned}$ | Not included |
| Radiotherapy <br> Yes <br> No | $\begin{array}{r} 1,207(55.0) \\ 929(64.1) \end{array}$ | $\begin{aligned} & 1.17 \text { (1.11-1.23) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.08 \text { (0.97-1.19) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 574 \text { (61.8) } \\ & 731 \text { (60.6) } \end{aligned}$ | $\begin{aligned} & 1.02 \text { (0.95-1.09) } \\ & 1 \text { (ref) } \end{aligned}$ | Not included |
| Chemotherapy <br> Yes <br> No | $\begin{array}{r} 850(68.2) \\ 1,286(53.6) \end{array}$ | $\begin{aligned} & 1.27 \text { (1.21-1.34) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.16 \text { (1.04-1.29) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 546 \text { (64.2) } \\ & 759 \text { (59.0) } \end{aligned}$ | $\begin{aligned} & 1.09 \text { (1.02-1.16) } \\ & 1 \text { (ref) } \end{aligned}$ | $\begin{aligned} & 1.05 \text { (0.97-1.14) } \\ & 1 \text { (ref) } \end{aligned}$ |
| Treatment complexity <br> 1 type of treatment <br> 2 types of treatments <br> 3 types of treatments <br> No treatment | $\begin{aligned} & 933(55.0) \\ & 685(60.1) \\ & 379(72.5) \\ & 139(48.4) \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.09(1.03-1.17) \\ & 1.32(1.23-1.41) \\ & 0.88 \text { (0.78-1.00) } \end{aligned}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 0.95 \text { (0.85-1.07) } \\ & 0.97(0.81-1.17) \\ & 0.90(0.78-1.04) \end{aligned}$ | $\begin{array}{r} 553 \text { (59.3) } \\ 413(60.3) \\ 249(65.7) \\ 90(64.8) \end{array}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.02 \text { (0.94-1.10) } \\ & 1.11(1.01-1.21) \\ & 1.09(0.96-1.25) \end{aligned}$ | Not included |
| Setting for follow-up <br> At hospital by a doctor <br> At hospital by a nurse <br> At hospital by a nurse and a doctor <br> At specialist practice <br> At general practice <br> Other places <br> More places | $\begin{array}{r} 1,640(58.8) \\ 77(58.8) \\ 224(60.1) \\ 8(38.1) \\ 17(50.0) \\ 6(26.1) \\ 127(61.7) \end{array}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.00 \text { (0.86-1.16) } \\ & 1.02 \text { (0.94-1.12) } \\ & 0.65(0.38-1.12) \\ & 0.85 \text { (0.61-1.19) } \\ & 0.44(0.22-0.88) \\ & 1.05 \text { (0.94-1.17) } \end{aligned}$ | Not included | $\begin{array}{r} 1,018(62.1) \\ 48(62.3) \\ 126(56.3) \\ 5(62.5) \\ 9(52.9) \\ 6(100.0) \\ 69(54.3) \end{array}$ | $\begin{aligned} & 1 \text { (ref) } \\ & 1.00 \text { (0.84-1.20) } \\ & 0.91 \text { (0.80-1.02) } \\ & 1.01 \text { (0.59-1.72) } \\ & 0.85 \text { (0.54-1.38) } \\ & 1.61 \text { (1.55-1.67) } \\ & 0.87 \text { (0.74-1.03) } \end{aligned}$ | Not included |

a) Adjusted for the covariates with $p<0.1$ in the univariate analyses.
needs. This indicates that the health-care system and health-care professionals are observant and responsive to needs that are common, whereas patients experiencing problems that are less common may not receive the same attention.

The national survey showed that more than $80 \%$ of the patients prefer meeting a doctor at the hospital for follow-up [12]. Even though patients prefer the traditional follow-up led by doctors at the hospital, the results of this study underline that there are no variations in the patient-perceived quality of care, as neither organisational nor treatment-related factors (e.g. type of treatment) seemed to be associated with patients reporting needs or unmet needs. Surgery and the followup setting were not related to having needs or unmet needs, and receiving chemotherapy or radiotherapy only showed a higher risk for needs. In the univariate analyses, more complex treatment procedures were associated with a higher risk of needs, but this trend disappeared in the multivariate analyses. The effect of the single treatment types (e.g. chemotherapy and radiotherapy) may overrule the effect of the treatment complexity. These results illustrate the importance of patient involvement and communication at the patient level where alternative models of follow-up are introduced.

## Strengths and limitations

A major strength of the study was its size, which ensures high statistical precision. Furthermore, the population was well-defined and represented patients diagnosed within a five-month period from all parts of Denmark. Finally, selection bias was minimised as the patients were identified in the NPR, in which 98\% of all cancer patients in Denmark are registered [14].

Although the response rate was high, differences between responders and non-responders might influence the results. The gender difference should be noted as the overrepresentation of females might partly explain why females were found to be more likely to have needs and unmet needs in this study.

Potential information bias could exist due to patients' recall bias. This might induce some misclassification, but this is assumed to be non-differential, which induces underestimation of the associations found. Further, the study focused on cancer patients who attended follow-up care. It has not been possible to determine whether the patients had completed their treatment or were still receiving treatment due to relapse or incurable cancer disease.

The questionnaire was pilot tested by qualitative interviews with cancer patients, but it was not tested quantitatively.

This study did not examine the possible associations
of interaction terms which was considered outside the scope of the study. Yet, as interactions may well be expected, the present study's results should only be taken as an indication of the true associations.

## CONCLUSION

When developing alternative strategies for follow-up care, the clinical aspect of ensuring timely detection of recurrence together with the physical and psychosocial dimensions must be considered. The present study underlines this issue by demonstrating that not all cancer patients have needs for support during follow-up; but for patients who need support, several factors seem to affect their needs and unmet needs.

In the light of these results, a more sustainable approach for the follow-up pathway may be a stratification model tailored to specific needs instead of the current "one size fits all" approach. The stratification should be based on the patients' disease-specific, physical and psychosocial needs, and the needs should be systematically assessed before the patients are transferred to followup care. In this context, more focus is needed on agespecific needs and the impact of co-morbidity. The NHS has been working with this approach and has developed a stratification model for follow-up combined with a holistic needs assessment and enhanced patient education, which has been tested on breast, prostate and colorectal patients [19, 20].
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