Assessment

Satisfaction with information provided to Danish cancer patients: Validation and survey results

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A B S T R A C T

Objectives: To validate five items (CPWQ-inf) regarding satisfaction with information provided to cancer patients from health care staff, assess the prevalence of dissatisfaction with this information, and identify factors predicting dissatisfaction.
Methods: The questionnaire was validated by patient–observer agreement and cognitive interviews. The prevalence of dissatisfaction was assessed in a cross-sectional sample of all cancer patients in contact with hospitals during the past year in three Danish counties.
Results: The validation showed that the CPWQ performed well. Between 3 and 23% of the 1490 participating patients were dissatisfied with each of the measured aspects of information. The highest level of dissatisfaction was reported regarding the guidance, support and help provided when the diagnosis was given. Younger patients were consistently more dissatisfied than older patients.
Conclusions: The brief CPWQ performs well for survey purposes. The survey depicts the heterogeneous patient population encountered by hospital staff and showed that younger patients probably had higher expectations or a higher need for information and that those with more severe diagnoses/prognoses require extra care in providing information.
Practical implications: Four brief questions can efficiently assess information needs. With increasing demands for information, a wide range of innovative initiatives is needed.

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1. Introduction

Patient-centered care is now recognized as a benchmark for high quality care [1] and information about treatment, care coordination and shared decision making are among the most important aspects of patient-centered health care [2–6]. Patients with fulfilled information needs generally have a better mental health-related quality of life and less anxiety and depression [7,8] although the causal relationship has not been established. Studies have shown high levels of unmet needs in the communication/information domains [9–11]. Health professionals are the most important source of information [12,13] and provision of information is one of the aspects of medical care where patients wanted most improvement from health professionals [14].

A large population-based study to investigate the nature and occurrence of needs of cancer patients in Denmark was conducted in 2005–2006 [15]. For this purpose, a questionnaire covering cancer patients' needs (The Cancer Patient's World Questionnaire, CPWQ) was developed based on information gathered during individual and focus group interviews with patients, relatives and professionals (described in more detail elsewhere [16]). Among the needs identified in the qualitative material was the need for information, which was covered by five items in the questionnaire elucidating key aspects of information that had emerged during the interviews (these items are called the CPWQ-inf). The items covered experiences from the full disease trajectory.

Our aim was three-fold: (1) to validate the CPWQ-inf, (2) to assess the prevalence of dissatisfaction with the information provided by health care staff to Danish cancer patients, and (3) to identify clinical and sociodemographic factors predicting dissatisfaction with the information.

2. Methods

2.1. Validation of the questionnaire

Five questions covered satisfaction with the information given (see item texts in Table 1).

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First, the questionnaire was validated by cognitive interviews including patient–observer agreement where 52 cancer patients were interviewed by telephone within 24 h after the patient had answered the questionnaire and placed it in a sealed envelope. During the telephone interviews, the questions were read aloud by the interviewer and the patients were instructed to answer the questions using their own words instead of the response format from the printed questionnaire. The interviewer asked the patients to elaborate their answers until the interviewer felt that she had received enough information to choose a response category. The printed questionnaire was returned to the Research Unit. The tape-recorded interviews were coded independently by two observers who did not have access to the patients' written responses given before the interview. The observers 'translated' the patients' oral answers into what they regarded as the most appropriate response categories. The observers were to accept the patients' norms and judgments when choosing a responses category. The results from the two observers were subsequently compared and a consensus version was made. This consensus version was compared with that of the patient from before the interview [17].

Agreement was evaluated first by quadratic weighted kappa, which is a coefficient of agreement corrected for chance agreement ranging from −1 to 1 [18] excluding the 'unknown/not relevant' category, and second by overall agreement defined as the number of times the same response category was used by patients and observers, divided by the times the item was answered by both parties. Items were accepted as valid without further analysis if the kappa value was above 0.60 (substantial agreement [19]) or the kappa value was below 0.60 but overall agreement was above 80% (acknowledging that kappa becomes artificially low if most answers to an item falls into one particular response category [20]). For each item, the response distributions were calculated separately for patient and observer consensus version and were compared using Wilcoxon signed rank test.

Second, traditional cognitive interviews [21] using probes based on the Question Appraisal System [22] were carried out to investigate how patients understand the questions, how they recall the information, which aspects they take into account when deciding on an answer, and how they plot this answer on the list of response categories. Seventeen patients who had not participated in the patient–observer agreement phase were interviewed face-to-face. The cognitive interviews have been described in more detail elsewhere [23].

2.2. Survey study population

Patient recruitment has been described elsewhere [16]. In brief, hospital departments treating cancer patients provided lists of all patients that had; (i) been in contact with that department within the past 12 months, (ii) had a diagnosis of cancer, (iii) were alive and (iv) lived in one of the three Danish counties Ringkoebing, Funen, and Copenhagen. From the two largest oncology departments 16% of all patients were selected (i.e., those born on the 23rd–27th of each month) and from all other departments 28% were selected (i.e., those born on the 23rd–31st of each month). In this way, patients from smaller departments were 'over-sampled' to allow reliable comparisons between types of departments. In the analyses, data was weighted to take the sampling into account (see section on analyses).

All 81 departments treating cancer patients in the three counties of interest were invited. From patient lists, patients were identified and invited to participate. Had the patient not responded within two weeks a reminder was sent out (Fig. 1). Information about the study emphasizing that participation was voluntary was included in the invitation letter. Along with the answered

questionnaire, the participants returned a signature indicating informed consent.

The study was approved by the Danish Data Protection Agency (No. 2004-41-4279) and the Scientific Ethical Committee (No. 01-116/03 and 11-071/04).

2.2.1. Survey analyses

Data were weighted to adjust for the unequal proportions of patients included from different departments using the PROC SURVEYFREQ procedure in the SAS statistical package v. 9.1 (i.e., patients from the two major oncology departments were weighted as 1.69 because patients with fewer birth dates in each month were included from these departments). In this way, the results correspond to those that would have been obtained if equal proportions had been sampled from all departments. Likewise, all regression analyses were weighted using the PROC SURVEYLO-GISTIC procedure.

Participants and non-participants were compared using ordinal logistic regression analysis excluding the 'unknown/not relevant' category.

Univariate analyses of the associations between background variables and dissatisfaction with the information were performed using ordinal logistic regression excluding the 'unknown/not relevant' category. The background variables were gender, age, marital status, education, employment status, diagnosis, stage, disease/treatment phase (a variable taking stage, time since diagnosis, and treatment into account), number of treatment modalities (i.e., surgery, radiation therapy chemotherapy, and hormone therapy), county, and type of hospital department. Subsequently, the background variables significantly associated with dissatisfaction with the information were entered in a multiple ordinal logistic regression model in which backward stepwise regression analysis was undertaken for model building.

Each analysis was based on subjects with no missing values for any of the variables included in the model ("complete case" analysis). The initial model included patients with no missing values in any of the background variables when backwards stepwise regression was undertaken. For each outcome, the final model was repeated for those patients with no missing values only in the background variables included in the final model. The final model (presented in the table) thus included more patients than the initial model. As the overall conclusions remained the same the missing values had not introduced biased findings.

Generally, a significance level of 0.05 was chosen.

3. Results

3.1. Validation of the questionnaire

Based on the patient–observer agreement study, items A–D were accepted as valid without further analysis as their Kappa values were above the predefined threshold of 0.60 (substantial agreement) [19] (Table 3). In item A and B regarding information at the time of diagnosis, the mean scores for patients and observers were distributed in a significantly different way but this mainly reflected that observers had often chosen the most satisfied category while the patients had chosen the second best category (in 13 cases) in item A and that observers had chosen the most satisfied category while the patients had chosen the second best (4 cases) or third best (5 cases) category in item B (data not shown). Item E had a low kappa of 0.34. However, the similarity of the mean scores of patients and observers and the high overall agreement of 88% suggested that this item performed well (Table 3) and that the low kappa value most likely was due to the highly skewed distribution of answers in this item with only two response categories.