Cross-sectorial cooperation and supportive care in general practice: cancer patients’ experiences

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Background. Cancer care usually involves several health professionals from different parts of the health care system. Often, the GP has an important role. Patients’ experiences of continuity and support may be related to characteristics of health care, disease or patients.

Objectives. To investigate Danish cancer patients’ experiences of their contact to the GP and the cooperation between the GP and the hospital.

Methods. A national cross-sectional questionnaire study in three representative counties of Denmark. Based on a review of medical records from all hospital departments treating cancer patients, a random sample of 1490 patients completed a validated questionnaire regarding patient experiences. A mixed methods approach was applied. Associations between patient experiences and background variables were analysed in ordinal logistic regression models and patients’ written comments were analysed qualitatively.

Results. One-third of the patients evaluated the cooperation between hospitals and primary care as suboptimal. Younger patients and patients from the capital Copenhagen were most dissatisfied. A third had needed support from their GP, and 41% of these patients had not fully received what they needed. Older patients, patients in Stage 1 and patients from surgical departments were least likely to have needed their GP’s support. Patients described support from the GP as empathic behaviour and help with coordinating health services.

Conclusions. A substantial number of cancer patients experienced suboptimal cross-sectorial cooperation and supportive care. Efforts to improve cancer care cooperation may focus on the possible supportive role of the GP as it seems that there is an untapped potential in primary care.

Keywords. Cancer, continuity of care, patient-centred care, primary health care, questionnaire design.

Introduction

Cancer patients often have to consult several different parts of the health system, and lack of continuity is a widespread problem in a fragmented health care system.1 The involved health care professionals often lack knowledge about the patients’ interactions with other parts of the health services.1–4 Inadequate cooperation may result from cultural barriers to communication, poor information transfer between health professionals in different settings and insufficient medical knowledge.5,6 It is often argued that the most consistent health professional throughout the cancer trajectory should be the GP who has the opportunity for staying in contact with the patient.7,8 Regarding patients with advanced and incurable cancer, primary care including GPs and community nurses has an additional important role in end of life care9–11 and numerous national and regional programmes are promoting high-quality palliative care in the community these years.12–15 Continuity of care is a feature of health services affecting cancer patients in all stages of disease, though. To fully understand the issue of continuity and to be able to create care that is patient centred, the patients’ perspective must be elucidated throughout the whole cancer continuum.

The purpose of the current study was to examine Danish cancer patients’ experiences of their contact to the GP and the cooperation between the GP and the hospital. We wanted to identify key problems on a national scale.
basis and to investigate whether any subgroups of patients are more exposed to poor experiences.

Methods

The questionnaire

Cancer patients’ needs and problems were initially assessed in a literature review. A suitable questionnaire covering all relevant issues could not be found. Consequently, to develop a new questionnaire investigating experiences from the patients’ point of view, an interview study was carried out. Focus groups and individual interviews were conducted with 77 individuals (patients, relatives, employees and volunteers from Danish Cancer Society and health care professionals) to identify substantial needs and problems among cancer patients. The new questionnaire ‘The Cancer Patient’s World’ (CPWQ) was developed on this basis, covering issues of patients’ physical, psychological and social needs during diagnostics and treatment. Four items (named items A–D in this manuscript) covered the patients’ experiences regarding cross-sectorial cooperation and support in general practice (CPWQ-GP) (Fig. 1).

The questionnaire was validated by patient–observer agreement and cognitive interviews. These cognitive methods together yielded detailed descriptions of patients’ interpretations of questions and response categories and the results showed that patients generally understood the items as expected indicating good validity (L. H. Lundstrøm, submitted for publication). Additional insights into the meaning of the items were obtained in the validation, and this knowledge is used in the present paper.

Study population

The target group was cancer patients aged ≥18 years who had been in contact with a Danish hospital because of their cancer during the past year. From February 2005 to January 2006, we sampled patients from all hospital departments treating cancer patients in three representative counties of Denmark: the capital Copenhagen, the rural Ringkøbing and the mixed rural/urban Funen (Appendix 1). A random sample of patients was selected by reviewing medical records of patients born on the 23rd to the 31st of any month, corresponding to 28% of all patients. However, at the two large regional cancer centres, only patients born on the 23rd to the 27th were selected, corresponding to 16% of patients from those departments. The differences in sampling proportions were chosen because most cancer patients were in contact with one of these two cancer centres. If we selected the same proportion of patients from all departments (and maintained the planned total sample size), rather few patients would be included from each of the smaller departments (i.e. all other departments than the two cancer centres) precluding reliable comparisons between departments unless the total sample was very large. We therefore sampled more patients from the smaller departments. A total of 2202 patients were invited to join the questionnaire study (Fig. 2).

Background variables of the patients, their disease and treatment were registered both from their medical records and from the questionnaire (Tables 1 and 2).

Quantitative data analysis

Ordinal logistic regression was used to compare participants with non-participants regarding background variables. Using items A–C as outcome variables, univariate analysis was performed and significant background variables were afterwards entered into a multivariate model by backwards stepwise multiple

![Figure 1](https://academic.oup.com/fampra/article/28/5/532/821720)
regression. The final model was tested by addition of the removed insignificant variables one by one. The association between items A and B was also analysed by entering item B in the final multivariate model with item A as the outcome. Odds ratios (ORs) were used as a measure of association. To adjust for the unequal sampling proportions across departments, data were weighted using the PROC SURVEYFREQ and PROC SURVEYLOGISTIC procedures in SAS 9.1. A significance level of 0.05 was chosen.
Qualitative data analysis

The answers to the open-ended question D were analysed using an inductive technique where the content was coded regarding themes. The purpose was to find meaningful categories in the comments and to elucidate patients’ expectations to their GP.
Results

A total of 1490 patients (68%) answered the questionnaire (Fig. 2). The response rate was lowest for the oldest and youngest patients and for patients with head and neck cancer, prostate cancer, lymphoma and leukaemia, cancer in Stage 4, from medical departments and from Copenhagen (Table 1). Self-reported characteristics are shown in Table 2.

Prevalences and predictors
Concerning item A (whether the patient had experienced good cooperation between the hospital/s and their GP), 31% of the participants answered ‘always’, 20% ‘most of the time’, 4% ‘sometimes’, 9% ‘rarely/never’ and 36% ‘don’t know/not applicable’. As ‘most of the time’ indicates that the satisfaction was not always good, the results can be summarized: almost a third were fully satisfied, a third (33%) were not fully satisfied and a third provided no evaluation. In univariate analysis, younger patients were more discontented than older patients up to 80 years, and patients from Copenhagen were more dissatisfied than those from Funen. Widows/widowers and old age pensioners were most satisfied (data not shown). In the multivariate model, the variables age, marital status and county remained significant (Table 3).

Concerning item B (whether the patient had needed help or support from their GP), 35% of the participants answered ‘yes’. Patients were less likely to answer yes if they were male, older (for patients aged ≥40 years), on old age pension or working full time, in Stage 1, from Copenhagen county, from surgical departments and had received few treatments (data not shown). Age, stage of disease and type of department remained significant in the multivariate model (Table 3).

Of those having needed help or support from their GP (item C), 57% stated that they had received what they needed ‘to a high degree’, 24% answered ‘to some degree’, 9% ‘to a poor degree’, 8% ‘not at all’ and 2% ‘don’t know’. There were no significant associations with background variables.

Items A and B were associated as follows: patients who had needed help or support from their GP were more likely to have experienced suboptimal cooperation between the hospital(s) and their GP [OR = 1.62 (95% confidence interval (1.23–2.13), P < 0.001].

Qualitative results
A total of 117 patients answered item D (about particular wishes to their GP), yielding 190 codes. In 17 of these, the patients expressed that their contact to the GP had been exclusively positive. Nine categories appeared after coding.

Empathy (63 codes). Patients described the psychological qualities that they wanted the GP to display in the doctor–patient relation. The patients looked for interest, engagement and open communication, e.g. time, talk, support and solicitude. Several patients mentioned that they wanted the doctor to show sensitivity and understanding towards the patient, take initiatives regarding the patient (e.g. consultations at home) and help sustain the contact to ‘keep in touch with how well or bad you feel’.

Some patients expressed their experience of the GP being busy and superficial as barriers in this regard:

It would have been nice if I could have had a personal talk with him—(I) miss more empathy and interest on his side. He has been far too busy at the few talks I have had.

Knowledge (26 codes). The patients wanted the doctor to know more about their disease, treatment and sequelae, in order to be sure of proper diagnostics, treatment, adequate examination and referral and to avoid delays, e.g. in diagnosis. Experiencing that the doctor was competent was important in order to feel safe:
I could feel safer if he knew something about my disease and the following calcium problems.

Guidance (26 codes). Several patients needed help of a more practical nature, e.g. with their physical symptoms and social matters such as their work and a sick note. One patient answered that she would have liked the doctor to be able to speak out for me at appointments with the municipality as I could not do it myself because of the disease.

... able to speak out for me at appointments with the municipality as I could not do it myself because of the disease.

Information (10 codes). Some patients asked for the hospital to communicate more information to the GP and also the GP to communicate more to the patient. The requested information concerned the disease itself, treatment, side effects, referrals, test results, prevention and the information that the GP received from other involved health professionals. Some patients had the experience that they themselves had to be a messenger between the involved professionals:

He only knows what I can tell.

Change of GPs (17 codes). This category was used in two contexts. Some patients had registered with a new GP because they felt that the former doctor had let them down in the form of malpractice, inadequate knowledge or lack of empathy:

Chose to change GPs in the middle of the chemotherapy as he expressed that I should pull myself together.

The first thing I did after the operation was to change doctors, and now I have a kind, understanding, professional, capable (...) GP

On the other hand, it could be a problem changing GPs in connection with a diagnosis of cancer:

Got a new doctor at the same time ... it was a hell to loose the safety provided by XX.

Malpractice (seven codes). Some patients described that their GP had made a mistake. These statements were characterized by anger and a feeling that the disease had been discovered later than necessary:

He should have referred me to the hospital the first time I consulted him. He just kept on saying that the lump was nothing for me to worry about.
and did not do anything. It was almost nine months before he referred me . . .

Service/structure (16 codes). Some patients experienced poor coordination in the cooperation between their GP and the hospital. They wanted to be referred to the right place, wanted their GP to know more about the routines of the hospital and wanted help coordinating the different parts of diagnostics and treatment:

An overview and an outline of the various specialists and ambulatory examinations during diagnostics.

Some patients wished to have a more continuous contact with their GP during the whole course of the disease, but several mentioned that they could not engage their GP in the treatment:

She has been quite uninterested . . . She said that everything related to my disease had to be taken care of by the hospital.

Several patients stated that the total wait to see their GP, the specialist doctor and the hospital had been long.

Other (18 codes). This category contained the statements that could not be coded in the other categories, e.g.:

Perfect treatment

Mistaken answers (seven codes). Answers that did not make sense.

Discussion

In this national cross-sectional study, a third of the cancer patients experienced cross-sectorial cooperation as suboptimal or problematic. The validation of the questionnaire showed that patients generally perceived this issue as a matter of the hospital providing information about diagnosis and treatment to the GP (L. H. Lundstrøm, submitted for publication). Concerning need for help or support from their GP, one-third had experienced such need and 41% of these patients were not fully satisfied with the help they received. Comprehension of ‘help or support’ included consultations, home visits, information, prescriptions for medicine, referrals, blood tests, check-ups and acupuncture (L. H. Lundstrøm, submitted for publication).

Younger patients, patients from Copenhagen and patients who had needed help or support from their GP were the most dissatisfied patients concerning cooperation, while widows/widowers were the most content. Patients who were older, in Stage 1, and from surgical departments were least likely to report a need for help or support from their GP.

The results indicate that cancer patients’ experiences of basic health care services such as provision of discharge summaries and common GP services are often dissatisfactory. Contrary to Danish health political goals of coordination of care,22 many cancer patients do not experience integrated care, and there is room for considerable improvement. Furthermore, GPs were only adequately in contact with a minority of cancer patients, which is somewhat surprising as GPs are commonly regarded as coordinators of individual cancer patient trajectories. These findings expose substantial weaknesses concerning cooperation and support in cancer care from the patient perspective and confirm other studies questioning the role of GPs in coordination of care.8,22,23

A large part of the patients (36%) answered ‘don’t know/not applicable’ to the question on the experienced cooperation between the hospital and the GP. Former studies including our own validation of the present questionnaire have also shown that many patients are not aware of the information transfer between health care professionals4,24 (L. H. Lundstrøm, submitted for publication). Another reason may be that the hospital has taken fully care of their treatment and that patients have not consulted their GP during the disease trajectory.75 Furthermore, cancer patients lack information about the cancer-related health services that may be offered by their GP.5 This lack of knowledge may contribute to the relatively low proportion of patients reporting a need for help or support from their GP.

The large proportion of patients perceiving cross-sectorial cooperation and the GP’s supportive care to be suboptimal is consistent with evidence demonstrating discordant perceptions among patients and health care professionals regarding responsibility for explicit tasks.1 These gaps in care management may lead to unnecessary distress in patients and poor quality of treatment as shown in the qualitative results.26,27

In the open-ended question concerning the GP, several patients expressed that they needed help with coordination throughout the disease trajectory. Other comments emphasized empathy, which also professionally is seen as a core element of general practice and patient centredness.28 The patients needed support during treatment and someone to listen to them. Several patients described an experience of strong empathy if the GP initiated contact whereas experiences of the doctor being busy or superficial were barriers to patients perceiving the doctor as being empathic. The other categories in the qualitative analysis further clarified how GPs can support cancer patients and attend to their needs. Overall, receptiveness to the
patients’ needs and willingness to respond to these needs including the psychosocial ones were the core wishes from cancer patients to their GP identified in this study.

The main strengths of the study are the reasonable response rate of 68% and the representativity of the participants who represented the spectrum of cancer diseases and stages and came from a wide range of settings. The recruitment procedure entailed a very complete identification of patients and a high participation of relevant departments (Fig. 2). The most significant non-response was found at the patient level and analysis of non-participation (Table 1) showed that differences in response rate between subgroups of patients were small. The highest proportion of non-participation was found among the most ill patients. However, the multivariate analyses did not demonstrate a clear association between degree of illness and suboptimal experiences. On the basis of these considerations, we judge the participants to be representative of the target group (adult cancer patients in contact with the health care system) and hence the results to be generalizable to all Danish cancer patients and probably also to cancer patients in other countries with comparable health care systems.

The limitations of the study primarily concern the design. The causality between different patient experiences remains uncertain in this cross-sectional study. Only longitudinal research designs can further clarify how patient experiences interact.

The current study is difficult to compare directly with other surveys because of the newly developed items. The advantage of these items is that they have been solidly validated and therefore yield credible knowledge.

Evaluations of patient satisfaction often have a high ceiling effect with up to 90% of patients being satisfied.25–31 The present survey did not show such high satisfaction rates, which may be caused by use of more specific questions compared to patient satisfaction questionnaires.

The patient responses in this study outline opportunities for health care providers to improve cooperation and support in cancer care. Also, health professionals may have difficulties seeing through the fragmented health care system.1 However, ideally the GPs should be in a position to be able to act as coordinators and to offer support throughout the course. A precondition is sufficient insight into diagnostics, treatment and procedures in the hospitals. This may be obtained through prompt and sufficient discharge summaries from hospital departments1 and by having standard procedures for cross-sectorial cooperation.32 Secondary care professionals may also involve GPs by referring patients to their GP in case of need for support and guidance.5 However, other studies indicate that mutual lack of recognition and acquaintance between GPs and hospital-based physicians are barriers to cooperation.22,33

Of patients claiming to have needed help or support from their GP, only 57% had received this sufficiently. As GPs are in a key position to give cancer patients the needed psychosocial care,34,35 this finding should be followed by considerations about how to improve patients’ experiences of support. Apart from being responsive to the patient’s needs and proactively offering support, the GP can help the patient access the relevant resources, e.g. information, emotional support or practical help. Given that, on average, each GP has only a few cancer patients, this goal seems realistic.36 Furthermore, health professionals from both primary and secondary care can provide information about patient associations and other sources of support outside the health care system.

Conclusions

This nationwide study shows that a large proportion of cancer patients experienced dissatisfactory cross-sectorial cooperation and suboptimal support from their GP. These findings call for interventions to improve patient-centred outcomes of cancer care. The goals for these interventions should be that professionals from primary and secondary care cooperate while keeping the individual patient’s needs in view and that patients know which health care professionals to seek when support is needed.

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Declarations

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Conflicts of interests: none.

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