Cancer patients’ perception of information exchange between hospital-based doctors and their general practitioners

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Abstract

Rationale, aims and objectives The quality of communication between health care professionals is a key issue determining health outcomes in cancer care. This study aims to find out what importance cancer patients in Austria attach to information exchange between hospital-based doctors and their general practitioners (GPs) and how patients perceive this flow of information.

Methods In this cross-sectional study, cancer patients seeking help at a community-based organization in the voluntary sector (Viennese Cancer League) were polled with a 16-item questionnaire. Contingency tables were evaluated by means of the chi-squared and Mantel–Haenszel test.

Results The mean age of the 252 respondents – 92.6% of those polled (272) – was 51.9 years (SD ± 13.6). 87.5% [female (f): 92.1%, male (m): 80.2%] considered the exchange of information between the hospital-based specialists and their GP ‘very important’ or ‘important’; 12.5% (f: 8.0%, m: 19.8%) ‘not so important’ or ‘not at all important’; 28.1% (f: 26.0%, m: 31.2%) of patients considered the flow of information as ‘very good’ or ‘fairly good’, but 50.9% (f: 58.7, m: 40.0%) as ‘rather poor’ or ‘poor’. Some 34.8% of patients thought that their cancer disease was first suspected by a hospital-based specialist; 42.1% thought that it was first suspected by a doctor outside the hospital. Even when patients were counselled elsewhere they gave high importance to the provision of appropriate information to their GP.

Conclusions Cancer patients in Austria attach high importance to the provision of appropriate information to their GP by hospitals and perceive this exchange of information as insufficient, a finding that could well be prevalent in other European health systems.
instrument for assessing cancer patients needs – has been developed and successfully validated [6]. In this Supportive Care Needs Survey (SCNS-SF34), the domain patients’ information needs are heavily weighted (11 out of 34 questions are devoted to that domain). The study of Boyes et al. also shows that cancer patients not in remission have significantly higher needs for information than those in remission. One study examining the needs of seriously ill patients with advanced cancer and chronic end-stage medical disease and of their next of kin has found that the most important elements related to end-of-life quality were ‘trust and confidence in the treating physician’, ‘disclosure of disease in an honest manner’, ‘avoidance of unwanted life support’, ‘symptom relief’ and ‘preparation for life’s end by resolving conflicts and saying good-bye’ [7]. Some of these issues call for the involvement of the patient’s general practitioner (GP).

Because the relevance of the information provided by GPs to cancer patients largely depends on the flow of information from hospital-based doctors involved in cancer care to GPs, difficulties in the information exchange between these professionals can influence patient satisfaction and health outcomes. The quality of information exchange among different professionals and between the patient and his or her doctors is therefore considered a key issue of the multidisciplinary approach to cancer care [8].

A recent study found that community practitioners expect to be better informed regarding the stage of the cancer, the prognosis and the level of information given to patients [9]. The hospital specialists, on the other hand, wish to be better informed about psychological problems or co-morbidity of the patients. The ‘gravity’ of a cancer diagnosis and the necessity of complex diagnostic and therapeutic procedures usually mean that a specialist will assume responsibility for the patient’s treatment, thereby tending to stress the biomedical model of health care [10], and sometimes favouring a top-down decision-making process by experts [10,11]. The patient, having been informed about his or her cancer disease, usually undergoes a psychological crisis and, in addition to specialized care, needs a doctor to whom he is connected by a long-standing doctor–patient relationship and who takes a bio-psycho-social approach to patient care [8,12,13]. This doctor of the patient’s trust often is the primary care doctor.

Our study aimed at finding out what importance cancer patients attach to the exchange of information between hospital-based specialists and their GPs and how they perceive this flow of information.

Methods

Settings and sampling

In order to answer the study questions we revisited the data of our study on breaking bad news to cancer patients [14], which included all patients who sought help at the Viennese Cancer League (‘Wiener Krebshilfe’) within an 18-month period. The Viennese Cancer League is a community-based institution in the voluntary service sector. It provides organizational and psychological support and information to cancer patients.

The patients in our survey were asked to fill in a 16-item questionnaire. Criteria for participation were the established diagnosis of a malignant tumour, a command of the language of the questionnaire (German) and a minimum age of 18. Patients’ eligibility for participation was verified by a clinical psychologist (KI). There was no selection by the institution that fielded the questionnaire in respect of sex, type and stage of cancer, or degree of suffering. Ethical approval by the ethic commission of the Viennese Cancer League was received.

Questionnaire

By means of a self-administered 16-item questionnaire, patients were explored concerning their perception of quality of communication between hospital-based specialists and their GPs (for the complete list of questions please refer to the parent publication of this article [14]). The questionnaire was given a field trial to test it for clarity and answerability before completion of the final version. To ensure comprehension of the questionnaire, a psychologist was available on-site to clarify patients’ questions when necessary. In addition to supplying sociodemographic data (age, sex, level of education, place of residence) and stating type of cancer the questions ‘For how long have you known about your cancer disease?’ (0–6 months; 6–12 months; 12–24 months; 2–5 years; longer than 5 years), ‘How important is the provision of appropriate information by the hospital to your general practitioner?’, ‘How good is the exchange of information between your general practitioner and your hospital-based specialist regarding your cancer disease?’, ‘Who first suspected that you were suffering from cancer?’, ‘Who informed and counselled you mainly about your cancer?’, ‘Who is your primary care physician?’ were asked.

In order to help patients understand the term ‘appropriate information’, they were asked in the questionnaire to consider whether they thought that their GP had been informed in writing or by personal contact (e.g. telephone) by the hospital doctor about their diagnosis and the recommended therapeutic procedures before the specific cancer therapies were started.

Austrian health care system

It seems necessary to mention some of the peculiarities of the Austrian health care system. Unlike most other European countries, Austria (and Germany) has a double system of specialist care: hospital-based specialists and self-employed specialists, the latter, like the GPs, being remunerated by the national health insurance system [15]. The primary health care system in Austria is very loosely regulated, leaving room for the patients to choose, more or less freely, whether they would like to see a GP in their surgery or a self-employed specialist or go to the outpatient ward of a hospital with their complaint (no gatekeeper function of GPs). GPs and self-employed specialists are fee-for-service providers; hospital-based specialists are salaried and thus there is no need for them to compete with GPs and self-employed specialists.

Data analysis

The statistic evaluation was carried out using the program package spss 9.1. The contingency tables were evaluated by means of the chi-squared and Mantel–Haenszel test. A two-sided P-value of <0.05 was regarded as statistically significant. We compared the subgroups of cancer patients with respect to age, sex and education.
Results

Of 272 consecutive cancer patients who were asked to fill in the questionnaire, 252 (92.6%) completed it. Of these, 151 (59.9%) were women and 91 (36.1%) men. Ten patients (4.0%) did not state their sex. The mean age was 51.9 years (SD ± 13.6 years). Table 1 shows the educational levels of participants, which was about the same as for the overall Austrian population. At the time of polling, 19.8% of patients had known of their cancer for 0–6 months, 34.4% for 6–12 months, 26.7% for 1–2 years, 13.8% for 2–5 years, and 5.3% for more than 5 years. Table 2 shows the origins of neoplasm in our sample.

Table 1 shows the answers to the questions by male and female participants. In order to facilitate a better understanding of the results, we have consolidated certain answers to categories. 28.1% of participants (f: 26.0%, m: 31.2%) stated that according to their subjective impression, the flow of information between the hospital doctor responsible for their cancer treatment and their GP was ‘very good’ or ‘fairly good’, 50.9% (f: 58.7%, m: 40.0%) stated that the information exchange was ‘rather poor’ or ‘very poor’ (chi-squared \( P = 0.062 \), no statistical significant difference between answers of male and female participants). Some 15.3% of female participants and 30.0% of male participant stated that they could not answer the question (\( P = 0.006, \) significant difference between genders). After controlling for age and education, this difference remained statistically significant (Mantel–Haenszel \( P = 0.020 \)).

Similarly, we consolidated the answers to the question ‘How important is the provision of appropriate information by the hospital to your general practitioner?’ Some 87.5% of participants (f: 92.1%, m: 80.2%) considered the exchange of information ‘very important’ or ‘important’, and 12.5% of participants (f: 8.0%, m: 19.8%) considered this exchange of information ‘not so important’ or ‘not at all important’ (\( P = 0.007, \) significant difference between answers of male and female participants (Mantel–Haenszel \( P = 0.007 \)). An age group comparison showed that patients under the median (53.6 years) gave higher importance to information exchange (\( P = 0.082; \) showing a trend, but no statistical significance).

Two hundred and forty-one patients (95.60% of all respondents) stated that their primary care doctor was a GP. In two cases (0.8%), the primary care doctor was a general internist. Nine patients (3.6%) had no primary care doctor.

Table 4 shows a correlation of the answers to the question ‘Who informed and counselled you mainly about your cancer?’ with the answers to the question ‘How important is the provision of appropriate information by the hospital to your general practitioner?’ We see that even when patients were informed and counselled mainly by hospital doctors or by self-employed specialists, they gave high importance to the provision of appropriate information to their GP. A comparison of cancer patients as regards education or professional training with their answers on ‘How good is the exchange of information between your general practitioner and your hospital-based specialist’ showed that there was no statistically significant difference (\( P = 0.360 \). After adjustment for age and sex, this difference was still found to be of no statistical significance (Mantel–Haenszel \( P = 0.081 \)).

Discussion

We see from our data that cancer patients attach high importance to the provision of appropriate information by hospital-based specialists to their GP and that they perceive the supply of appropriate information by the hospital-based specialists to the GP as insufficient. A vast majority (87.5%) of participants considered the exchange of information ‘very important’ or ‘important’. Female cancer patients attach significantly more importance to information and communication than male patients (92.1% female vs. 80.2% male in our study population), which is in line with some of the existing research in this area [3,16,17].

In contrast to the high importance patients attached to the provision of appropriate information to GPs by hospital-based specialists, 50.9% of cancer patients stated that, according to their perception, the information exchange was ‘rather poor’ or ‘very poor’, and only 28.1% of participants thought that it was ‘very good’ or ‘fairly good’. It could be argued that our data reflect only patients’ subjective impressions. Nevertheless, we think that this subjective impression represents patients’ satisfaction and might well reflect reality. Therefore, there should be a cause of concern also with respect to timely shift of curative oncological to palliative care.

Table 1 Educational levels of participants \( n = 252; \) mean age 51.9 years, median 53.6 (SD 13.6)

<table>
<thead>
<tr>
<th>Educational level</th>
<th>( n ) (%)</th>
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<tbody>
<tr>
<td>Completed academic training</td>
<td>13.3%</td>
</tr>
<tr>
<td>School leaving examination</td>
<td>24.4%</td>
</tr>
<tr>
<td>Completed vocational school or apprenticeship or skilled craftsmen/woman</td>
<td>45.0%</td>
</tr>
<tr>
<td>Other form of professional training</td>
<td>2.3%</td>
</tr>
<tr>
<td>Uncompleted formal education</td>
<td>15.0%</td>
</tr>
</tbody>
</table>

Table 2 Origins of neoplasm in our sample

<table>
<thead>
<tr>
<th>Primary tumours</th>
<th>( n ) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer</td>
<td>84 (33.3)</td>
</tr>
<tr>
<td>Malignant lymphoma</td>
<td>21 (8.3)</td>
</tr>
<tr>
<td>Cancer of colon and rectum</td>
<td>20 (7.9)</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>17 (6.7)</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>15 (5.9)</td>
</tr>
<tr>
<td>Uterine cancer</td>
<td>12 (4.7)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>10 (4.0)</td>
</tr>
<tr>
<td>Oropharyngeal cancer</td>
<td>10 (4.0)</td>
</tr>
<tr>
<td>Laryngeal cancer</td>
<td>9 (3.6)</td>
</tr>
<tr>
<td>Thyroid cancer</td>
<td>9 (3.6)</td>
</tr>
<tr>
<td>Testicular cancer</td>
<td>9 (3.6)</td>
</tr>
<tr>
<td>Malignant brain tumour</td>
<td>6 (2.4)</td>
</tr>
<tr>
<td>Ovarian cancer</td>
<td>6 (2.4)</td>
</tr>
<tr>
<td>Pancreatic cancer</td>
<td>6 (2.4)</td>
</tr>
<tr>
<td>Bladder cancer</td>
<td>4 (1.6)</td>
</tr>
<tr>
<td>Osteosarcoma</td>
<td>3 (1.2)</td>
</tr>
<tr>
<td>Liver cancer</td>
<td>3 (1.2)</td>
</tr>
<tr>
<td>Stomach cancer</td>
<td>3 (1.2)</td>
</tr>
<tr>
<td>Renal cell carcinoma</td>
<td>3 (1.2)</td>
</tr>
<tr>
<td>Oesophageal cancer</td>
<td>2 (0.8)</td>
</tr>
<tr>
<td>Total</td>
<td>252 (100.0)</td>
</tr>
</tbody>
</table>
Our findings from Austria are in line with the findings of Milliat-Guittard et al. who reported that community practitioners in France wanted to be better informed of the stage of the cancer, the prognosis and the level of information given to patients [9]. McConnell et al. conducting semi-quantitative interviews with oncologists, referring surgeons and GPs in Australia, found that the latter two groups of doctors identified delay in receiving the consultant’s reply letter as of greatest concern and that they need information regarding the proposed treatment, expected outcomes and any psychosocial concerns; these items, however, are often omitted [18]. They concluded that consultants and referring doctors need to review and modify their letter writing practices. Our data, based on patients’ perception on the quality of information exchange, confirm these findings from Australia.

The questions contained in our questionnaire did not allow to specify at which period of the cancer care continuum they were aimed (diagnosis and treatment phase, post-treatment phase, end-of-life phase), but we can see from the results that 54.2% of patients had known about their cancer disease not longer than 1 year. Finney Rutten et al. have found in their review that more than a third of the 112 articles on cancer patients’ information needs and sources included patients from multiple phases of the cancer care continuum [3].

Suspicion of cancer

As perceived by the patients in our study, hospital-based specialists (34.8%) played a highly important role in first suspecting that a specific patient was suffering from cancer, followed with about the same percentage by self-employed specialists (22.3%) and GPs.
Nevertheless, we would like to put the data into the right perspective by pointing out that a GP or a self-employed general internist, suspecting cancer in one of his or her patients, would tend to save the patient from premature worries by keeping the suspicion to himself or herself and referring the patient for further testing to a community-based specialist or to a hospital. The perception of patients might therefore wrongly reflect the primary care doctors’ importance in first suspecting cancer. Adding up self-employed specialists and GPs, 42.1% of patients thought that their cancer disease was first suspected by a doctor outside the hospital, which demonstrates the high importance of out-of-hospital care in detecting cancer (Table 3, Question 3). According to our data, a significant role is played in suspecting cancer by patients’ relatives (7.3%) and ‘other persons’ (15.8%).

One surprising aspect of patients’ answers to the question ‘Who informed and counselled you mainly about your cancer?’ is that 7.7% stated that the person performing this task was neither a doctor nor a relative. Our data do not specify which persons/professionals constitute this 7.7%, but we assume that health professionals such as nurses are among them.

**Strength and limitations**

Our survey and analysis focus on the issue of an appropriate supply of information by hospital-based specialists to GPs and did not cover the important question of transfer of information from community-based practitioners to hospital-based specialists. Furthermore, the issue of the appropriateness of the content of discharge letters [19], sent by hospital-based specialists to GPs, could not be raised. We used patients who sought help at the Viennese Cancer League, a voluntary, community-based institution providing support, information and counselling to cancer patients. We consider it an advantage that patients were polled in a setting independent of hospitals and self-employed doctors, because they could feel free to state their impressions and opinions without feeling obliged to say good things about the people from whom they had just received medical attention. However, a selection bias cannot be excluded, active patients being more likely to turn to the voluntary service sector than those who adopt a defensive attitude towards their illness. More research using representative samples is needed to determine the generalizability of these findings.

Summing up, we think that the considerable deficiencies in the information exchange between hospital-based doctors and GP in cancer care in Austria, as highlighted by this study, could well be prevalent in other health systems in Europe. Lack of timely information exchange may lead to increased risks for undesirable treatment outcomes (e.g., repeated testing, complications due to ignorance about patients’ allergies or response to specific pharmacotherapy). The GP, in many cases acquainted with the patient for many years, has a humble but important role to play and needs to be informationally connected to oncologists. Although the expertise for cancer treatment is with the oncologists, it is necessary that, in order to maintain optimum patient management, oncologists refer patients back to the GP, supplying them with a medical letter, preferably before commencing cancer therapy.

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**References**