

# Patient satisfaction in outpatient cancer care: a prospective survey using The PASQOC<sup>®</sup> questionnaire

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## Abstract

**Study objectives** To examine how outpatient cancer patients assess their cancer care in private oncology practices and day hospitals, and to identify the extent to which staff meet the expectations of their patients.

**Setting** Private practices ( $n=41$ ) and day hospitals ( $n=8$ ) in Germany, including 16 “repeater” practices who had already participated in the 2002 Patient Satisfaction and Quality in Oncological Care (PASQOC)<sup>®</sup> survey.

**Participants**  $n=4,615$  patients with cancer. Diagnoses: 25% breast cancer, 21% colorectal cancer, 12% haematologic malignancies, 11% lymphomas; mean age 63.5 years; 57% female;  $n=1,639$  patients from repeater practices.

**Measurements** The 2004 PASQOC<sup>®</sup> questionnaire contained 63 problem-oriented items which covered 15 different dimensions of care. Practice staff invited their patients to participate and surveys were mailed to all sampled patients. For statistical analysis, the problem frequency (PF) was calculated for each item.

**Results** Of 5,600 patients who received the questionnaire, 4,615 replied (response rate: 82%). The best results were

obtained for the dimensions “further support in daily life” (3% PF), “nurses” (5% PF), and “physician-patient-relationship” (8% PF). Potential for improvement was most pronounced for “handling of side effects” (39% PF), “partnership and shared decision making” (30% PF), “side effects” (30% PF) and “communication with other patients” (26% PF). Considerable differences in PFs between practices were observed. Mean results from the 16 repeater practices revealed only few changes compared to the 2002 PASQOC<sup>®</sup> survey, although some practices had greatly improved their performance.

**Conclusions** The PASQOC<sup>®</sup> questionnaire identified strengths and weaknesses of outpatient care for cancer patients. By providing a comparison with other practices, PASQOC<sup>®</sup> can help staff of individual practices to improve their performance.

**Keywords** Outpatient care · 2004 PASQOC<sup>®</sup> questionnaire · Problem frequency-cancer

## Introduction

In recent years, patients have increasingly been considered as consumers or customers in the healthcare system. Consequently, awareness has risen of how patients perceive the quality of their care. Patients can evaluate many of the core qualities of a doctor’s performance, and gathering feedback from patients is gaining credibility as an approach to assessment [1]. Moreover, the patient’s perspective about their experience of care can markedly vary from those of healthcare professionals and might contribute to improvement [2–4]. On the other hand, patients have limited ability to assess the medical quality of care, as documented in a recent study that found no correlation between patients’ evaluations of the quality of technical care and the results from a review of case records using evidence-based indicators [5].

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Patient feedback surveys are increasingly seen as a key component of quality monitoring to assess healthcare services [6]. Findings from such surveys are available from many European countries, as well as from the UK, USA, Canada, and Australia [1]. Nearly one half of the high-level executives in US disease management organisations regarded patient satisfaction as “very important” to the long-term success of the industry [7]. Health service researchers, healthcare providers, and regulators have declared patient satisfaction a measure of healthcare quality [7].

Instruments measuring patient satisfaction have been developed according to specific standards with respect to questionnaire content, design and development, as well as reliability and validity [6]. Development of the PICKER patient surveys began more than 20 years ago. Meanwhile, many hospitals have used these questionnaires, and the performance of the UK National Health Services was investigated using PICKER surveys. For cancer patients, a general survey (not specifically acute care or ambulatory) was developed in the late 1990s, which also served as the foundation for the Picker Ambulatory Oncology Survey Instrument in Canada [8].

The questionnaire used in the present study was a successor of the Patient Satisfaction and Quality in Oncological Care (PASQOC) 2002 survey which had been established in cooperation with PICKER Germany and with the German Cancer Society [9]. We asked patients to report on their experiences of clinical care during the most recent consultation using questions which gave details on what actually occurred (i.e. “Were you given information about any side effects?”). This produces more reliable results than the patient’s evaluation of what occurred [10].

Using the PASQOC® 2004 questionnaire, we aimed to examine how ambulatory cancer patients assess their medical care in private oncology practices and day hospitals to illustrate the extent to which staff meets the patients’ expectations. Furthermore, comparing different oncologic facilities might identify particular strengths and weaknesses of individual centres. The results of the survey should assist the practice team to introduce specific quality improvement measures. Consequently, repeater practices who had already taken part in the 2002 survey could measure the changes achieved within 2 years.

## Patients and methods

### Patients

Patients were recruited from 41 private oncology practices and 8 day hospitals in Germany. Between October 1, 2004, and January 31, 2005, staffs from each practice were asked

to invite 130 consecutive patients to participate in the survey and to obtain permission to submit the patient’s address to the study centre (PICKER Institute Germany). Fourteen practices did not manage to include 130 patients and recruited as few as 40 to 121 patients for the survey. Of 6,564 eligible patients, 487 (7.4%) refused to participate. A total of 477 (7.3%) patients were formally excluded by protocol because (a) they were not considered eligible by practice staff assessment (short contact, e.g. collection of prescription etc.;  $n=160$ ), (b) severity of disease (Karnofsky index  $<40\%$ , modified Karnofsky index  $>5$ , ECOG index  $>3$ ;  $n=38$ ), (c) age  $<18$  years ( $n=2$ ), (d) mental retardation ( $n=26$ ), (e) inadequate language skills ( $n=106$ ) or (f) other reasons ( $n=145$ ). In total, 5,600 patients participated in the study.

### Questionnaire

The PASQOC® questionnaire was developed between 1998 and 2002 in cooperation with the German Cancer Society, the KOK (Conference of Nurses in Oncology) and PICKER Germany. The construction of the 2002 questionnaire was described previously [9]. In brief, PASQOC® relates to 15 different dimensions of patient satisfaction:

1. Physician–patient relationship
2. Communication with physicians
3. Co-management and shared decision making
4. Nursing staff and other practice assistants
5. Pain and pain treatment
6. Handling of side effects
7. Involvement of family members and friends
8. Exchange with other patients
9. Practice organisation
10. Additional information
11. Further support in everyday life
12. Practice environment
13. Side effects (specific symptoms).

The majority of the items were report questions which ask about the patients’ experience. The respective answers were given on nominal or ordinal scales [for example, question 23, “In the practice, can you openly discuss very personal things with your doctor?” Yes, always–Sometimes–No–I did not need/want this (so far)]. In addition, there were also some rating questions (e.g., question 47, “In the practice, I find the personal atmosphere...” Excellent–Good–Reasonable–Bad–Not important). Each item was assigned to one of the 15 different dimensions of patient satisfaction. The questionnaire provided a list of 16 specific side effects/symptoms (from nausea to changes in character) and the option to tick “other”. As a special service for partici-

pating patients and practices, a section to provide a free-text response was annexed to the PASQOC® questionnaire (not included in the database).

Before the present survey, the 2002 PASQOC® questionnaire had been modified quantitatively with respect to internal validity, discriminatory power and item difficulty. After removing 40 questions (including former dimensions 13 and 14), the 63 remaining items still covered the full range of performance of healthcare professionals and the 15 dimensions of patient satisfaction.

The study centre mailed the PASQOC® questionnaire directly to the 5,600 patients who had given their permission to take part. Patients also received pre-paid return envelopes addressed to the German Picker branch. If patients had not responded after 2 weeks, they received a reminder letter. After another 2 weeks with no response, the questionnaire was mailed a second time. The screener questionnaire used to recruit patients at the practice site included, besides formal consent and patient's address, information about therapeutic intent, primary site of the tumour and metastases, as well as current therapeutic approach (e.g. chemotherapy, radiotherapy...).

#### Anonymity and data protection

Written patient consent to participate was sought in the practice setting. Full anonymity was secured, i.e. further contacts as well as second and confirmatory consent were only directly with Picker Institute. Picker secured anonymised data handling according to the data protection act. Consequently, it was not possible for either physician (or sponsor) or other practices to identify patients. This non-interventional study was only executed in Germany and needed at the point in time no ethical approval.

#### Statistics

Data from the completed questionnaires were stored in the study centre in an SPSS 11.5 for Windows database file (SPSS, Chicago, IL, USA, 2000). Descriptive statistics were computed and problem frequencies were defined for each item. First, the responses to each question were grouped as to whether they indicate a performance problem or not, resulting in a dichotomous problem score. For example, only the answer "Yes, always" to question 23 (see above) would indicate no problem, whereas both "No" and "Sometimes" were regarded as deficient performance of the physician. The problem frequency (PF) was calculated for each question by adding up the percentages for the answers indicating a problem. Second, the mean PFs for each dimension were calculated using the PFs of all items belonging to the respective dimension. To identify factors which had an influence on overall patient satisfaction, beta

values were calculated using multivariate regression. Student's *t* tests for independent samples were used to identify differences between 2002 and 2004, and a *p* value of <0.05 (two tailed) was considered statistically significant.

For the comparison of results between 2002 and 2004, only those items were analysed, which were included in both versions of the questionnaires, and the 2002 results were re-analysed accordingly. Each practice received the results from their own patient cohort, together with a report of the whole study and tables with anonymous results of other facilities.

## Results

The PASQOC® questionnaire was mailed to 5,600 patients. The return rate was 82%: 43% of patients had responded to the initial mail, 30% after the first reminder and 9% after the second reminder. Although the response rate differed between practices (range: 73 to 92%), 96% of practices achieved a response rate of >75%.

#### Patient demography and clinical characteristics

The mean age of the patients was 63.5 years, and there was a slight preponderance of females (57%, see Table 1). Colorectal cancer and breast cancer were the most frequent diseases found in nearly half of the patient cohort, as expected by the profile of patients treated in a private practice. Palliative treatment was the most frequent aim of treatment (59%). Of all the patients, 84.2% had received chemotherapy, 61.0% had undergone surgery, 32.1% had received radiation therapy and 8.0% received both chemotherapy and radiotherapy.

#### Dimensions of patient satisfaction

The extent of patient satisfaction varied considerably between the 13 different dimensions (Fig. 1). The best results were obtained for "further support in everyday life" (dimension 11), "nursing staff and other practice assistants" (dimension 4) and "patient physician relationship" (dimension 1), with PFs of only 3, 5 and 8%, respectively. In contrast, considerable room for improvement was observed with respect to dimensions 6 (handling of side effects, 39% PF), 13 (side effects, 30% PF) and 3 (co-management and shared decision-making, 30% PF).

Regarding specific questions, some items had extremely good results with more than 90% satisfied respondents. Most of these questions belonged to dimensions 1 and 4. For example, only 4.7% of patients reported problems with empathy and friendliness of their physician. Perhaps surprisingly, only 2% stated that their physicians gave

**Table 1** Patient demography and disease parameters (percentages)

	2004		2002
	Total	Repeater	First time
Number of patients ( <i>n</i> )	4,615	1,639	1,826
Gender			
Male	40.0	47.0	42.9
Female	57.0	50.9	55.0
Not defined	3.0	2.0	2.0
Age (years)			
18–35 years	3.0	2.0	2.0
36–54 years	20.0	17.8	20.3
55–64 years	25.9	26.2	30.3
65–74 years	33.0	34.5	30.3
74+ years	13.5	15.8	13.5
Not defined	5.4	3.7	3.7
Mean age	63.5	63.6	62.4
Primary tumour			
Colorectal	20.6	24.3	21.5
Breast	25.0	18.6	20.4
Lymphoma	11.1	13.7	17.6
Blood	11.6	13.4	12.0
Lung	6.1	4.1	3.3
Others	23.6	23.3	21.5
Not defined	2.0	2.6	3.6
Therapy target (reported by staff)			
Palliative	59.1	61.0	58.2
Aftercare	15.6	18.4	19.1
Adjuvant	17.3	14.3	14.0
Curative	6.7	4.3	6.8
Not defined	1.4	2.0	1.9
Total number of visits in the practice			
More than 40	28.6		
21 to 40	25.0		
11 to 20	21.2		
1 to 10	23.0		

incomprehensible replies to their questions (e.g. “med speak”), and only 7% reported that their physician had insufficient time for the consultation. The three items on the performance of nurses (dimension 4), friendliness, answers to questions and confidence, had very low PFs of only 2 to 7%. The items with the highest PFs are depicted in Fig. 2. Most questions regarded the patient’s satisfaction with information on side effects, pain or shared-decision making.

#### Side effects (dimension 13) and handling of side effects (dimension 6)

As expected from a patient group receiving chemotherapy and radiation therapy, side effects were frequently reported (Fig. 3). More than 50% of patients complained of fatigue, alopecia or nausea. Insomnia and weight loss were other frequent problems. The mean number of side effects was 5 per patient. The severity of fatigue was associated with the number of side effects reported per patient. Combinations

of side effects were common and often correlated with each other, such as nausea and vomiting ( $r=0.54$ ). Of the patients, 38% reported pain, and 39% of these complained of severe pain.

Many medical professionals did not meet their patients’ expectations with respect to handling of side effects and managing pain. These topics received the highest scores during the survey (see Fig. 2). For example, question 38, “Has the probability of side effects been discussed before the start of treatment?” had a PF of 49%, and no item of dimension 6 had a PF below 34%. Also, when patients were asked directly whether they wished to receive more information about side effects, 27% answered “yes” (question 46.3). Of the patients reporting pain, 47% felt that they had not received enough support for self treatment of pain at home (question 32), 41% stated that side effects of pain treatment had not been adequately discussed (question 34) and 77% had not used a pain diary (question 31).

Patients who reported side effects were significantly less satisfied with their healthcare professionals (data not shown). This effect was observed in most dimensions and was particularly strong for patients with pain, insomnia or gastrointestinal side effects.

#### Partnership and shared decision-making (dimension 3)

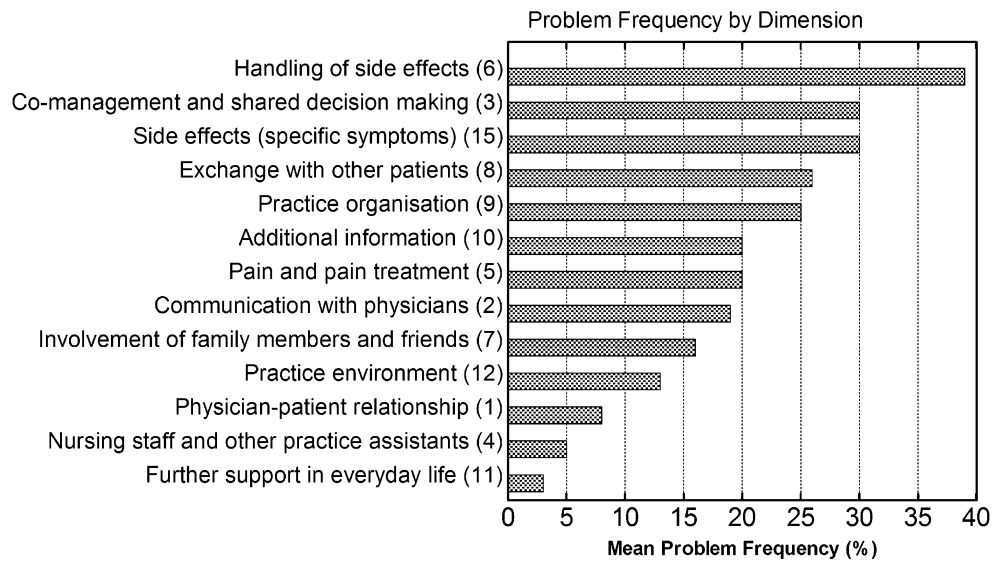
Question 18, “Who has defined your treatment plan?”, had a PF of 48%, indicating that every second patient was not involved in decision making. Of patients, 29 and 24% stated they did not feel fully informed about their disease (question 20) or about their current treatment (question 21), respectively. Only 5% of patients did not want to take part in decision making (question 19). Many physicians appeared not to regard the patient as an expert for his or her body because the respective item (question 24) had a PF of 34%. Nevertheless, as stated earlier, patients were generally very satisfied with their physician–patient relationship. The percentage of patients who did not respond to questions of dimension 3 was between 1.2% (question 20) and 6.7% (question 24).

#### Differences between practices and practice ranking

The performance of medical staff varied substantially in the patients’ perspective. With respect to specific questions, there was a large range of PFs. For example, copies of laboratory results were not provided by 5 to 65% of practices (mean PF: 34%), and handling of side effects differed between PFs of 16 and 67%.

A ranking of practices was established by calculating quartiles of PFs. When the seven highest- were compared with the seven lowest-ranking practices, the results were significantly different ( $p<0.05$ ) with respect to particular

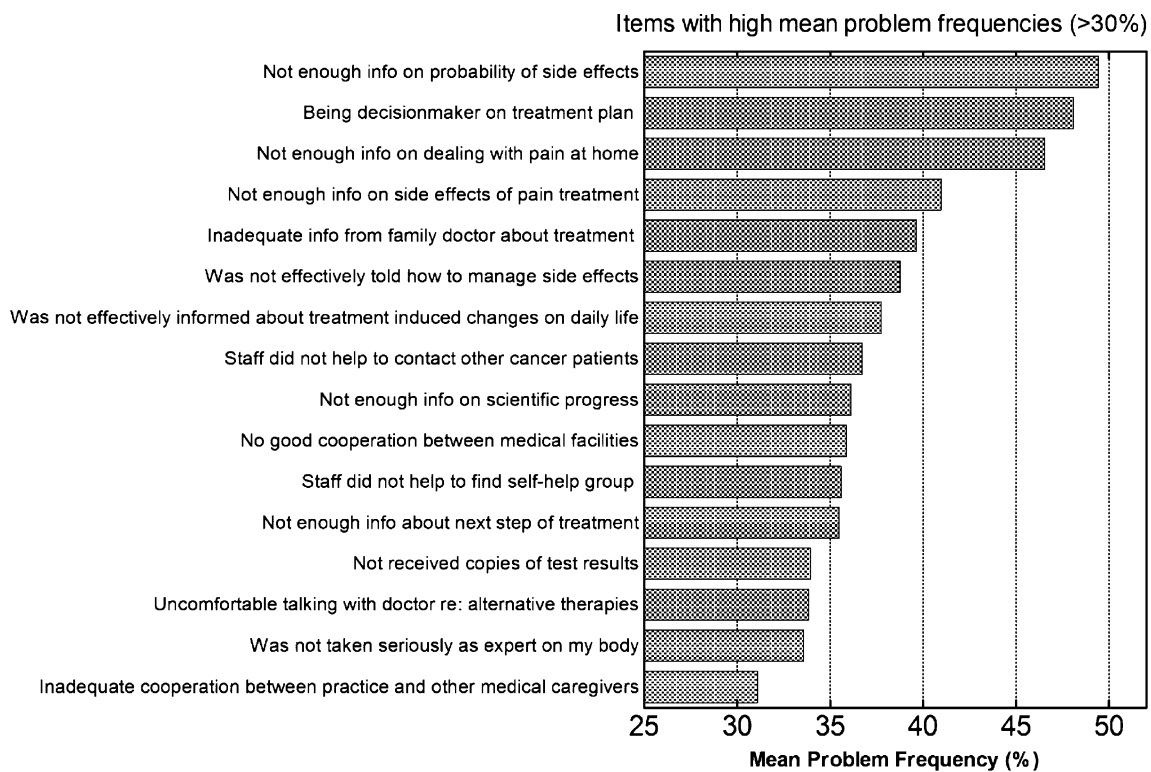
**Fig. 1** Mean PFs are given for each dimension of the PASQOC questionnaire. The calculation of PFs is explained in the text



patient characteristics: patients in the lowest-ranking practices were younger (mean age: 62.4 vs 65.0 years) and experienced a higher number of side effects (mean: 5.7 vs 4.8 per patient), and higher proportions of these patients had breast cancer (35.4 vs 19.9%), received adjuvant therapy (27.2 vs 14.6%), had been hospitalised during the preceding 12 months (70.0 vs 58.8%) or received combination therapies. Of the eight day hospitals taking part in the survey, four belonged to the seven lowest-ranking facilities.

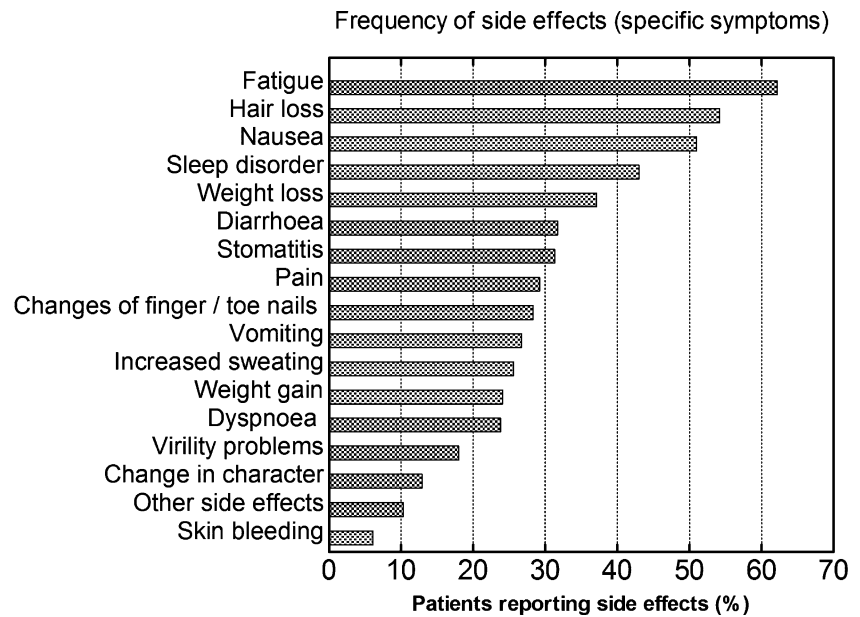
Changes between 2002 and 2004

Sixteen centres had already taken part in the PASQOC® 2002 survey. When the results of the two studies were compared, no clear trends in favour of a general improvement were observed: five centres showed improvements in five or more of the 13 dimensions, whereas six showed deteriorations in at least five dimensions. Considering PFs, a significant ( $p < 0.05$ ) improvement was only observed for dimension 9, practice organisation (improvement by two



**Fig. 2** Specific items of the PASQOC questionnaire with mean PFs of >30%

**Fig. 3** Percentage of patients who reported side effects of treatment



points, from 29 to 27% PF), while two dimensions deteriorated from 2002 to 2004 (side effects, +2% PF, and handling of side effects, +4% PF). In spite of these disappointing results, some practices had greatly improved their performance after they had implemented quality improvement measures and changes in their professional processes.

#### Overall satisfaction

As in other PICKER surveys, the question “Would you recommend the practice to friends and relatives?” was used as an indicator of overall patient satisfaction. The mean PF was 23.9%, with 73.3% of patients responding “Yes, without restrictions”, 22.8% responding “yes, probably” and 1.1% responding “no”.

The willingness to recommend the practice was significantly associated with the dimensions physician–patient relationship (standardised regression coefficient beta: 0.22), practice environment (beta 0.20), partnership and shared decision making (beta 0.15) and practice organisation (beta 0.10). Taken together, these and other dimensions with lower beta values were able to explain 38% of the variance for overall patient satisfaction.

#### Discussion

The PASQOC® survey aimed to examine how cancer patients assess their ambulatory oncology care at private practices and day hospitals, and to identify to what extent medical professionals meet their patients’ expectations.

Quality improvement in practices was not the primary focus of the study. The high response rate of 82% shows that patients were very receptive to providing feedback about their experiences. Overall, outpatient care was well received by cancer patients. The survey identified, however, specific strengths and weaknesses of ambulatory care: While nurses and physicians received high ratings of patient satisfaction, some issues emerged which should be improved in the patients’ perspective. First, a considerable proportion of patients felt they should be more involved in cancer care decisions, as reflected by the dimension “partnership and shared decision making” with a PF of 30%. Second, there was a lack of information on the handling of side effects (39% PF), while the occurrence of side effects per se was regarded less problematic (30% PF). “Communication with other patients” (26% PF) and “Organisation of the practice” (25% PF) also had considerable PFs.

The investigated patient cohort, i.e. 4,615 subjects from 49 facilities, can be considered a representative sample of ambulatory cancer care in private oncology practices. To our knowledge, no other comparable study has included more sites. The number of patients was only surpassed by the investigation of Gesell and co-workers on 5,907 cancer outpatients from 23 hospitals [11]. Compared with the 2002 PASQOC® survey [9], the number of both patients and sites nearly doubled. The preponderance of females, which was also reported by other authors [8, 11, 12], is often seen in healthcare survey research. We achieved an exceptionally high response rate of 82%, being some 20% higher than that reported in other surveys [8, 11, 13]. Therefore, the potential for a selection bias is low. Also, the distribution of

cancer diagnoses parallels the usual frequency of diseases in the population.

The PASQOC® 2004 questionnaire meets important criteria of questionnaire development [1]: It contains questions on key content domains of interpersonal skills, communication of information and patient engagement, as well as on overall satisfaction. There was a thorough process of development of the questionnaire, including the views of patients, by establishing focus groups and cooperating with the German Cancer Society. Tests of validity and reliability were carried out and led to a modification of the PASQOC® 2002 instrument. Furthermore, as common to PICKER surveys, the wording of the questionnaire is generally clear and straightforward. Many respondents had also used the free text fields for personal suggestions on what to retain and what to change in their oncology practice. Furthermore, the fact that the large majority of invited patients filled out the questionnaire supports the notion that this instrument meets the needs of cancer patients.

Another advantage of the PASQOC® 2004 questionnaire is that it contains both general and disease-specific questions. It has recently been advocated by the Disease Management Association of America Patient Satisfaction Workgroup [7] to use a “custom module” which focuses on issues specific to a particular patient group. There is also some overlap with questions contained in the Canadian Picker Ambulatory Oncology Survey Instrument [8]. This questionnaire could be used for examining transnational differences in patients’ perceptions of care.

Our survey identified specific subjects for improvement of ambulatory care. Deficiencies in physician–patient partnership and decision making were mentioned frequently. It appears that several physicians do not regard patients as experts for their own disease nor as partners through the treatment process. This finding, however, is not new. More than 25 years ago Cassileth reported that cancer patients preferred open communication about their illness and desired a maximum amount of information [14]. Handling of side effects was another problematic area. In many cases, information on side effects was not given, or it was presented in a way regarded inadequate by the patients. In a recent investigation in Germany, respondents also required more information on side effects [12].

The dimension “partnership and shared decision making” had a significant influence on overall patient satisfaction, which is a prerequisite for recommending the practice to relatives and friends. Other groups who investigated the interaction between physician and patient reported that doctors who encouraged their patients to discuss health information and ask questions received higher patient satisfaction scores [15]. A literature review disclosed that the physician’s understanding of the patient’s expectations is

critical to patient satisfaction [16]. Mandatory for this to occur is a communication style facilitating the exchange of ideas between patient and doctor.

Other dimensions relevant in this respect were “handling of side effects” and “practice environment”. The latter was also considered important by other authors: In a large multi-specialty medical group in northern California, the organisational variables “waiting time to see the doctor” and “courtesy of the non-physician office staff” explained 20% of the variance in patient satisfaction [17]. US cancer outpatients ranked waiting time and ease of reaching office among the top six priorities for service improvement [11].

We observed different degrees of patient satisfaction between facilities. An anonymous ranking of sites was calculated such that staff could use PASQOC® to compare their results with those of other practices. In one site which introduced quality improvement measures after the 2002 survey, PASQOC® 2004 revealed significant improvements in many dimensions, showing that this instrument is sensitive enough to disclose changes. The mean results of the 16 repeater practices, however, were strikingly similar to those of the 2002 PASQOC® survey. PASQOC® was not part of a general effort to improve patient satisfaction, and individual practices decide how they use the information.

In a survey in the Netherlands, general practitioners first received feedback from patients and then were informed how to interpret the results and how to plan improvements [3]. As an unexpected result, the patient’s satisfaction did not significantly increase after the intervention. Therefore, simply giving doctors the results of patients’ feedback does not appear to be effective for instigating change [3]. In a Swedish clinic for women with breast cancer, efforts to improve care were introduced between the two points of assessment, 2001 and 2004. As a consequence, significantly better results were obtained in 2004 compared to the previous survey [18]. Improvements in doctors’ performance were also observed when patients’ feedback was integrated into educational programmes with the results made available to the public [10].

The present study has some limitations. First, the primary aim was to provide healthcare professionals with a specific and easy-to-handle feedback from their patients. This resulted in the calculation of “problem frequencies” for each question by adding up the percentages of those answers which represent poor performance. By doing this, Likert scales were converted into dichotomous responses, and part of the information given by patients was lost. The advantage of this approach, however, was that it facilitates comparisons between different sites. An alternative would have been to convert the Likert values into a scale with a theoretical minimal value of 0 or 1 and a maximal value of 100. However, this would pose the problem of how to assess the distance between different responses, e.g. between

“good” and “very good”. Second, PASQOC® does not disclose the causes for impaired patient satisfaction. These could only be detected by discussions between professionals and patients in the respective facility. Third, because PASQOC® was specifically designed for oncological ambulatory care in the German healthcare system, it remains difficult to compare the degree of satisfaction in the present patient cohort with that of other chronically ill patients or with that of cancer patients from other countries. Yet, a significant proportion of questions are common to other PICKER questionnaires. Therefore, these could be used for comparisons with other patient cohorts, provided the results of specific questions are made available to other researchers.

In conclusion, the present survey in a large cohort of cancer patients described the patients’ perception of ambulatory care. The PASQOC® instrument was well accepted by patients. It enabled healthcare professionals to identify both strengths of care and issues with a need for improvement. It also revealed large differences between facilities and provided results for benchmarking. Thus, this questionnaire is of great value for future assessments of patient satisfaction, and medical professionals can use this instrument to determine the effects of their quality improvement measures.

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