

Patient satisfaction instruments for cancer clinical research or practice

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Cancer patient satisfaction assessment is increasingly considered, owing to the need to assess evolving patterns of care organization and delivery or to test new cancer treatments and interventions. This article reviews cancer patient satisfaction questionnaires using key methodological criteria. In total, 17 patient satisfaction instruments validated for the field of oncology during the period of 1999–2009 were identified from previous literature reviews and a literature search. Most of these instruments were developed with the input of the target population, relating to various cancer care contexts or treatments, and demonstrating reasonable psychometric performance. Future endeavor should address the appropriate comparison and interpretation of satisfaction data across cultures/languages, cancer treatment or care programs.

KEYWORDS: cancer • clinical research • cross-cultural adaptation • patient satisfaction • psychometrics • quality of care • validation

In the last few decades, patient satisfaction has become an important end point in healthcare quality assessment. It has been used not only to monitor the quality of the overall care but also to compare different treatments, patterns of care or healthcare systems [1].

Satisfaction or dissatisfaction with care can also influence patient behavior and, consequently, impact on the result of care. Good patient–professional healthcare communication promotes satisfaction [2], and satisfied patients have appeared more likely to comply and cooperate with medical treatment [1,3,4]. There is some evidence that satisfaction is also directly related to improvement in health status [5]; indeed, patient satisfaction has been shown to promote quality of life in cancer patients [1].

Traditionally, healthcare quality evaluation was mainly based on objective criteria [6]. The rise in the prevalence of chronic diseases has required expanding the healthcare focus to patient-centered care and patient's empowerment, taking into account individuals' psychosocial context, values and healthcare behaviours [7]. Investigating patients' point of view regarding their overall healthcare experience represents an important form of participation, providing patients with the opportunity to influence the quality of care [8].

Patients and clinicians do not necessarily agree about the quality of the care provided and the priorities for care improvement. For patients, the importance of receiving care that rates high in patient centeredness, in addition to being high in technical quality, has been underscored [9]. Hence, patients' judgement may have additional value when establishing the quality of care [10].

Relevance of patient satisfaction assessment in oncology

Cancer treatments are often long and associated with frequent interactions and increased dependency on healthcare providers from various specialities. In this context, a patient's satisfaction with the relief of treatment adverse effects and their experience of continuity of care, and relationship and communication with caregivers, need to be considered.

Patient satisfaction with treatment is a growing area of research, especially for chronic diseases [11]. This assessment may be particularly useful among outcome measures for cancer clinical trials or disease management programs.

Constant progress in antitumour or supportive treatment programs requires regular attention to patient satisfaction in oncology. Cancer patients are generally confronted with treatment alternatives accompanied with different profiles of

adverse effects. Consequently, an overall indicator such as patient satisfaction, encompassing different aspects of the treatment experience, may be particularly useful. For example, early-stage breast cancer surgery (i.e., mastectomy vs breast conserving therapy) shows no difference in a primary clinical outcome (i.e., survival); however, the risks and benefits of either breast conserving surgery or mastectomy vary and, thus, satisfaction with the treatment received will depend on patients' perception of the attributes and outcomes associated with the different surgical procedures [12].

Conceptualizing patient satisfaction

Definitions

Patient satisfaction, satisfaction with care, treatment satisfaction or perceived quality of care consist of terms referring to a consumer's reaction to their healthcare experience. Examples of measuring tools in the cancer field comprise of questionnaires that address patients' satisfaction with discrete aspects of medical treatments [13], or those focusing more on systemic aspects of healthcare services [14,15]. While perceived quality is defined as an appraisal of overall excellence or superiority [16], satisfaction is regarded as a positive affective response from the respondents [17] as fulfilling expectations, needs or desires [18].

Embedded in the broader satisfaction with care concept, treatment satisfaction refers to 'a recipient's rating of or report on salient aspects of the process and the results of his or her treatment experience according to predefined criteria' [11]. Treatment satisfaction is distinct from treatment preference, which is rather assessed before treatment administration and usually refers to a function or weights for adjusting years of life for differences in health status [11].

Expectations

The first theories on patient satisfaction comprised the idea of a comparison between a perceived quality of care and a personal standard as set by expectations or individual needs [19]. Patients would determine their own needs of care on the basis of a variety of personal characteristics (e.g., educational attainment), attitudes (e.g., fatalism) and prior experiences, coupled with the knowledge and information they receive from healthcare professionals but also from other patients, relatives or various other sources (e.g., reputation of the healthcare entity or knowledge of what may be expected) [20]. From these factors, a set of expectations about care outcomes, caregiver's behaviour and the performance of the system is formed. These expectations form the subjective standard against which care actually received is judged to be satisfactory or not satisfactory. It must be stressed that these expectations are subject to many changes during the course of the cancer trajectory [20].

However, patients' expectations and healthcare needs are multiple. The interactions between patients, health professionals and services are complex, and the dependency, uncertainty and anxiety involved in these interactions are likely to influence patients' judgement. Studies have evidenced that high patient satisfaction levels were unrelated to the experience of care [21], highlighting the complexity of patient satisfaction interpretation.

Components

Many studies of satisfaction subdivide their measures (or items) according to Donabedian's classic differentiation of structure, process and outcomes [19]. The structure refers to the physical environment and physical facilities of the service; the process addresses the interactions with the healthcare professionals and services. Patient satisfaction may be considered as an outcome of care such as health status but also an indicator of the healthcare process quality.

An increasingly large consensus has been reached concerning a multidimensional concept of satisfaction [20,22]. Various characteristics of healthcare professionals and services have been shown to influence satisfaction, and patients may develop distinct opinions in relation to each of these characteristics. The interpersonal aspects of healthcare (art of care) are generally considered to be an essential dimension (or domain) of satisfaction [11,23].

Doubts have been raised on the aptitudes of patients to assess the technical aspects of care (science of care); however, a positive relationship between a patients experiences and the quality of clinical care has often been observed [24].

A study conducted in Australia in 232 cancer patient's receiving outpatient treatment demonstrated greater importance attributed by patients to the technical quality of medical care, the interpersonal and communication skills of doctors and the accessibility of care [25].

With regard to treatment satisfaction, aspects of care to consider are related to factors that contribute to treatment preference and adherence [11], including expectations of treatment efficacy and side effects, medical care, management of side effects, treatment modality or dosage form [13].

Assessing cancer patient satisfaction

Whether in the context of cancer clinical research or practice, patient satisfaction assessment can be performed at various levels:

- Medical examination, treatment (e.g., medication or surgical procedure) or psychosocial intervention (e.g., communication skills training);
- Model of healthcare organization for a particular group of patients (e.g., organization of palliative care);
- Department (e.g., day hospital);
- Healthcare system.

Evaluation of patient satisfaction at the department or hospital level can provide results in terms of identification of sources of dissatisfaction with care and priorities in the choice of quality-of-care improvement initiatives; they can also constitute databases for benchmarking. Quality-of-care improvement actions can then be evaluated over time by using the same patient satisfaction evaluation tools [26]. Treatment satisfaction assessment may highlight reasons for adherence or preference for treatment or determine the optimal treatments to be recommended.

Considering the relevance of cancer patient satisfaction assessment, this article aims to describe patient satisfaction questionnaires specifically validated for the field of oncology

and addressing treatment or cancer care services. Further steps for the development or refinement of these measures are suggested.

Methods

Literature search

Patient satisfaction instruments that were specifically validated for the field of oncology in the past 10 years (from 1999 to April 2009) and addressing treatment or overall healthcare services were identified from previous literature reviews [5,23] and from a literature search undertaken on Medline with the search terms 'patient satisfaction' combined with 'outcome assessment (healthcare)' or 'treatment outcome' or 'outcome and process assessment (healthcare)' and 'neoplasms' (2006–April 2009), limited to adults aged older than 18 years and peer-reviewed publications in English.

Questionnaires that were not included in the list are those that addressed cancer genetic testing and screening services or the surveillance phase of cancer, patients' preferences or one aspect of care only (e.g., involvement in treatment decision making, information, satisfaction with informed consent).

Descriptive criteria

The list of patient satisfaction questionnaires are described along with key criteria that were derived from published documents on the development, validation, translation/adaptation of health status measures [27–29]. Reviews or analyses of cancer

patient satisfaction questionnaires were also consulted to more specifically address psychometric issues in patient satisfaction measurement [5,23].

These criteria are briefly summarized in TABLE 1. The rationale for and the population for which the questionnaire is designed are first formulated. A conceptual model is a description of the concepts that a measure is intended to assess and the relationship between those concepts [27]. A measurement model operationalizes the conceptual model in an instrument's scale and subscales. To appropriately measure healthcare provision or, more specifically, the effect of treatment, and address the specific patients' concerns or priorities, it is important that the relevance and comprehensiveness of the items to compose the instrument be assessed by the target population.

An instrument assessing a subjective concept should be psychometrically validated – its reliability (i.e., extent to which scores are free from measurement error), validity (i.e., ability to measure what is intended to be measured) and its responsiveness (i.e., ability to detect change) should be investigated. Tests of reliability include assessment of internal consistency using Cronbach's α -coefficient, and reproducibility or test–retest. Minimal standard for reliability coefficients are 0.70 for group comparisons [27]. From a psychometric perspective, the validity of an instrument can be assessed by investigating *a priori* hypotheses on the relationships between items constituting the instrument or between the instrument's scores and other outcomes. The former

Table 1. Key issues for evaluating the rigour of patient satisfaction tools.

| Item's property | Definition | Specific criteria |
|---|--|---|
| Conceptual and measurement model | The rationale for and description of the concepts and the population that a measure is intended to assess are provided. The relationship between concepts is indicated | Clear description of the purpose of the questionnaire, the target population, the concepts to be measured Provides information on the dimensionality and distinctiveness of scales Target population and experts were involved in item generation/selection |
| Psychometric performance | The instrument demonstrates psychometric performance: Reliability: internal consistency, reproducibility Validity: construct, convergent and discriminant validity (scaling success) Known-group difference Responsiveness Scale variability: floor/ceiling effects | Adequate sample size for psychometric study (7 items and ≥ 100 subjects) Cronbach's α -coefficients overall and per dimension 0.70–0.95 Intra-class coefficient or weighted $\kappa \geq 0.70$ At least 75% of results in accordance with hypotheses (i.e., item-convergent validity: $r \geq 0.40$; item-discriminant validity: item more highly related to own scale than other scale); evidence of questionnaire ability to differentiate between extreme patient group or to assess change over time Absence of ceiling effect or more than 15% of respondents at highest possible score |
| Burden | The instrument used is acceptable to patients, of adequate length and item wording (i.e., maximize response rate and completeness of data) | Level of missing data or refusal rate provided |
| Cultural and language adaptations or translations | The instrument adaptation/translation allows for conceptual/linguistic equivalence | Adaptation/translation is performed according to documented methods |
| Questionnaire use and refinement | Continued maintenance | Used in clinical studies and is regularly revised for content and psychometric performance (e.g., revised scoring, shorter version and specific-item modules) |

can be performed by exploring the measurement model underlying an instrument using factor analysis (e.g., principal component analysis and exploratory or confirmatory factor analysis) or multitrait scaling analysis [27]. The latter can be investigated by estimating correlations with other measures or by comparing the instrument's scores in relevant predefined subgroups. Assessment of responsiveness involves statistical estimation of effect size statistics. A final step of psychometric validation can be constituted of analyses enabling interpretation of score to be supported, such as the definition of a 'meaningful' level of change (minimally important difference), where meaningful is considered as the minimal change perceived as important by the individuals concerned.

To ensure acceptability to patients and so maximize response rate and completeness of data, during the questionnaire development process, repeated pilot tests of the questionnaire phrasing have to be performed. These include cognitive interviews investigating how well respondents understand the items and response sets, as well as language differences [23]. These also contribute to ensuring the validity of the instrument. Moreover, the questionnaire length should balance requirement for comprehensiveness and burden on the patient. For application across country languages, these questionnaires have to be translated and adapted according to standardized guidelines [30].

Finally, it is important that instruments are used, adapted or revised to more adequately and validly address specific population needs or concerns and adapt to the development of new cancer treatments or healthcare delivery services.

Results

In total, 17 patient satisfaction measures were included in the review (TABLE 2). A general description is provided in the following sections.

Instrument purpose, target population, content & format description

Most patient satisfaction instruments validated in oncology address components of the structure or process of the overall care [14,15,26,31–42]. Only three questionnaires specifically evaluate treatment, either intravenous and/or oral chemotherapy, biological or hormonal therapy [13,43] or breast [44] or head and neck surgery [45] considering both the process of care and treatment outcomes. Different patient satisfaction instruments were validated for one cancer site only [32,41,44,45].

Instruments address in- and/or out-patient services [14,26,31,36,37,46] or the oncology consultation [34,35]. One questionnaire bears on aspects of care in relation to the overall trajectory of breast cancer care [42]. All these are intended to be used while under or shortly following treatment, or in the weeks following hospital discharge; patients are then surveyed from the cancer care institution. One questionnaire was administered at least 6 months after diagnosis, recruiting patients from cancer national registries [38].

Some instruments only include items referring to the interpersonal or communicational aspects of the interaction with providers, reflecting particular attention to patient-centered care

requirements [34,37,39–41]. Others also involve satisfaction with technical skills or physical care [14,15,26,31–33,36,42,44,46].

Although not necessarily comprehensive (i.e., addressing overall aspects of care), all questionnaires' content is based on a multi-dimensional framework and, most frequently, on a taxonomy pertaining to the structure, process or outcome of care. One instrument refers to a conceptual model of patient satisfaction as a response to care expectations [13], and some address the impact of satisfaction on behaviors such as the intention to recommend the hospital or adhere to treatment or healthcare service [13,26,31,35,45].

Different instruments use an evaluative rating scale, generally on a five-level scale, to assess degree of satisfaction, agreement regarding an aspect of care [13–15,26,32,34,36,41,42,44], care frequency (e.g., 'never' to 'always') [13,33,40,41] or amount options (e.g., 'not at all' to 'very much' or 'extremely') [39,45]. Some questionnaires use response scales with various verbal descriptors [13,37,40,46]. Visual analogue scales [46] or dichotomous items (e.g., yes/no) [40] can also be found. Two instruments are constructed on patient-centered reports, where patients are asked to report on a process of care and whether that process of care met a certain standard, using frequency response scales [37,40].

Developmental modes

Most of the instruments reviewed were originally specifically designed for the oncology field. However, four measures were initially developed for general medical services and subsequently assessed for psychometric performance in the cancer target population [32,37,38,41]. One questionnaire's items were adapted from a family member version [47] and psychometrically tested for patients [15]. Questionnaires originally developed in the cancer field underwent an extensive process of development, including oncology patients and experts qualitative interviews for item generation/selection and cognitive debriefing for content validity or item wording clarity assessment [13,14,26,31,34,36,37,39,44–46].

Less recent questionnaires used conceptual frameworks and empirical (factor analysis) methods to identify satisfaction domains [33,38]. One questionnaire rested on evidence-based clinical guidelines [40].

Psychometric performance

All studies carried out psychometric testing on sample sizes larger than 100 patients. Most psychometric studies reported internal consistency estimates for the questionnaire overall scale or subscales, evidencing Cronbach's α values above 0.70. Less acceptable estimates appeared for subscales, such as treatment convenience [43], care access [14], hospital environment [48] or for one questionnaire different subscales [41]. Test–retest was only performed in seven studies also highlighting values above 0.70 except for specific subscales, such as expectations of therapy [43], general satisfaction [14], specific items [42] or for one questionnaire different subscales [41].

Aspects of validity assessment included construct or convergent validity, concurrent/discriminant validity or known-group comparisons. Both exploratory or confirmatory factor analyses and multitrait scaling analyses were carried out. Items convergent

validity evidenced generally high estimates. Fewer factors demonstrated better psychometric performance in revisions of factorial questionnaire structure [15,35,38]. Scaling successes of at least 75% were reported in five studies [14,31,42,43,45]. Less satisfactory results were found by Arraras [48], especially for the care organization and services subscales. Goodness of fit for the measurement model was found by Pusic [44] and Loblaw [35].

Concurrent/discriminant validity was assessed with scales bearing on quality of life, eating satisfaction, performance status, anxiety/depression, mental health, medical interview satisfaction and perceived quality of care. Patient satisfaction scores revealed low correlations with instruments assessing concepts different to patient satisfaction, such as quality of life [14,15,34–37,39,41–43].

Only five studies provided information on ceiling effect. Trask evidenced a ceiling effect for the 'expectations of therapy' subscale (21%) [43]. For Brédart [14] and Arraras [48], all but 'waiting time', 'access' or 'environment' subscales revealed a ceiling effect of at least 15%; whereas for Lubeck, all subscales [41] and Defossez, 31 (out of 63) items [42], revealed a ceiling effect of at least 15%.

Satisfaction mean score differences could be observed between patient groups using different specific criteria, such as age [41,42,45], gender [45], education [42], cancer stage [39,41], perceived change in cancer [43], presence of side effects [43], care expectations met, and intention to recommend the healthcare service [14] or treatment compliance [46].

As for interpretation of satisfaction scores, very little research was reported. Trask computed estimates of meaningful differences on the Cancer Therapy Satisfaction Questionnaire (CTSQ), calculated as 0.5 standard deviation of baseline scores and 1 standard error of measure (SEM), as well as the size of differences between group mean scores using known-group differences, such as perceived change in cancer over the past 2 weeks or presence of side effects due to medication [43].

Patient burden

Most questionnaires, whether addressing the oncology setting, surgical intervention, medical consultation or nursing care, encompassed 29–66 items. Three questionnaires comprised fewer items: questionnaires addressing therapy satisfaction [43,45] or palliative care [15,39,40] and one questionnaire included 120 items [37].

Out of 17 psychometric studies, 11 reported a response rate with most questionnaires displaying more than 70% and two others between 60–70% respondents. The BREAST-Q evidenced a 65% response rate at a second assessment [44]. The satisfaction survey, recruiting patients from cancer registries, exhibited a 50% response rate [38]. Nine studies accounted for item omission expressing the median percentage of item omission, which ranged from 1.6–7% [14,31,36,39,40]; one study evidenced that one to four items were missed by up to 22% patients [15]. In these questionnaires, items with highest missing responses pertained to the communication on psychosocial issues, ease of access, waiting time or experience of treatment.

Cultural/linguistic adaptation

Three questionnaires were simultaneously developed in different languages and cultures [13,14,31]; two questionnaires were simultaneously psychometrically tested in several languages/countries [14,31] and six others, including specific language versions of the later, were subsequently psychometrically tested [38,48–52]. No information on the translation procedure was provided for two questionnaires [38,53].

Kritsotakis revised item grouping for the Comprehensive Assessment of Satisfaction with Care nursing interpersonal and communication scales – Greek version; some satisfaction with interpersonal skills' items were more appropriately related to the technical skills domain in these patients [49]. Hagedoorn did not find support for the original distinction between communication, interpersonal manner and time spent with doctor and found that a three-factor model, technical competence, access to care and interpersonal manner (combined with communication and time spent with doctor), was more appropriate for the data [38].

Use & continuous maintenance

Two studies reported revised factorial questionnaire structure [35,38] and one provided factor analysis of a patient-adapted questionnaire version [15]. One questionnaire was psychometrically re-assessed for local use [54]. Eight questionnaires were used in one [34,37,38] or more cancer clinical studies [14,15,31–33]. These were based on observational, cross-sectional [55–57], longitudinal [58–62] or interventional design [63,64].

Expert commentary

This review evidenced that a number of patient satisfaction questionnaires rigorously developed and with reasonable psychometric properties are now available for cancer clinical research or practice. Most of these were specifically developed for the cancer patient population, with input of the target population, hence allowing for particular cancer concerns to be addressed. Four questionnaires are generic patient satisfaction questionnaires that compare healthcare services provided to different types of illness but may miss specific cancer patients' issues.

Patient satisfaction tools for various care contexts (i.e., medical or nursing care, in- or out-patient care, oncology consultation, palliative care or specific treatment, such as chemotherapy, breast or head and neck surgery) are now available. The development of various satisfaction instruments is justified by the critical requirement that an instrument is adapted to the context in which it is used. However, similar issues (that could be considered as generic/core patient satisfaction issues) are addressed in questionnaires in terms of information provision, technical or interpersonal skills, whereas specific issues are assessed depending on the type of health providers, type of treatment or stage of disease. Rather than being comprehensive and addressing overall care aspects, some of the reviewed questionnaires focus on particular care domains, such as interpersonal skills, hence being useful to specific research or clinical objectives.

Across questionnaires, psychometric performance could be demonstrated, especially in terms of internal consistency, construct (item convergent) or discriminant (low correlation with

Table 2. Description of cancer patient treatment satisfaction or satisfaction with care questionnaires.

| Instrument | Country (sample size ^a) | Purpose/assessment time/type of cancer | Length | Aspects of care assessed | Response options/scoring |
|--|--|---|---------------------------------|--|--|
| Cancer Therapy Satisfaction Questionnaire (CTSQ) [13,43] | France, USA, UK (n = 361) | Breast, colorectal, lung cancer patients perception of chemotherapy, after cycle of chemotherapy, biological or hormone therapy | 16 items | Expectations of cancer therapy, feelings about side effects, oral cancer therapy adherence, convenience, satisfaction with cancer therapy, stopping cancer therapy and reasons for nonadherence | 5-level Likert scale, addressing frequency, convenience, worth, difficulty, expectations met and satisfaction |
| Patient-reported outcome in breast surgery (Breast-Q) [44] | USA (n = 1950) | Patient-reported outcomes in breast surgery postsurgery | 63–66 items | Satisfaction with breasts, outcome, information, surgeon, medical team or office staff | Various types and levels of responses (e.g., agree/disagree, satisfied/dissatisfied); summary score on 1–100 scale |
| Patient Outcomes of Surgery-Head/Neck (POS-Head/Neck) [45] | UK (n = 250) | Patient-report outcomes of surgery for head–neck skin cancer postsurgery | 3 items | Operation result/expectations met, speed of recovery and willingness to recommend the same operation | 3- to 5-level Likert scales from ‘all the time’ to ‘none of the time’; or ‘not at all’ to ‘extremely’ |
| Patient Satisfaction with Healthcare for Prostate Cancer (CaPSURE Satisfaction measure) [41] | USA (n = 228) | Prostate cancer patient satisfaction with healthcare providers seen during the past 3 months | 15 items | Overall satisfaction with care, contact with providers, confidence in providers, communication skills, humaneness and willingness to participate in decision making | 6-point scale from ‘definitely yes’ to ‘definitely no’ or ‘very often’ to ‘not at all’ |
| Patient Satisfaction Questionnaire (PSQIII) Dutch version [38] | Validated for oncological care in the Netherlands (n = 1594) | Patient satisfaction with specific aspects of process of care in oncology setting, 6–24 months after diagnosis | 36 items out of 51 | Technical competence, interpersonal manner, communication, time spent with doctor and access to care | Statements/aspect of care rated on 5-point Likert scale from ‘strongly disagree’ to ‘strongly agree’ |
| Satisfaction with care among nonmetastatic breast cancer patients (REPERE-60) [42] | France (n = 820) | Nonmetastatic breast cancer patients satisfaction with the care provided during the different phases of the cancer care trajectory, more than 1 month after treatment | 60 items | Access to primary care, secondary care, competence/communication skills of primary care doctors, secondary-care doctors, choice of doctor, qualities of doctors, global satisfaction, cover for medical expenses, listening abilities/information by doctors, organization/follow-up, psychological support and material environment | 5-level Likert scale, from ‘poor’ to ‘excellent’, ‘strongly agree’ to ‘strongly disagree’ |
| Chinese Patient Satisfaction Questionnaire (ChPSQ-9) [32] | China (n = 222) | Hepatocellular carcinoma patient satisfaction with hospital services at first outpatient visit | 9 items (and 20-item long form) | Patient satisfaction with doctors, nurses and other staff’s clinical service | 5-point Likert scale ‘very satisfied’ to ‘very dissatisfied’ |
| Oncology Patients’ Perceptions of Quality Nursing Care Scale (OPPQNCS) [33] | USA (n = 436) | Oncology patients perception of nursing-care quality during active treatment | 45 items | Nurse responsiveness, individualization, coordination and proficiency | 6-point Likert scale ‘never’ to ‘always’ + ‘didn’t matter’, ‘don’t know’ |

^aOriginal psychometric study sample size.

Table 2. Description of cancer patient treatment satisfaction or satisfaction with care questionnaires (cont.).

| Translation/cultural adaptation | Evidence of acceptability | Evidence of reliability | Evidence of validity | Studies using the questionnaire |
|--|--|---|---|---------------------------------|
| Simultaneously developed in France, the UK and USA | | Cronbach's α : 0.60 (convenience)–0.87 Test–retest: 0.56 (expectation of treatment)–0.82 | 100% item-convergent 98% item-discriminant Low r with QLQ-C30 Known-group comparisons effect sizes: 0.28–0.84 Ceiling effects: 4–21% (expectation of treatment) Minimally important difference: 5.9–8.3 | |
| Developed in five centers in USA and Canada | Response rate: 72% 2nd assessment: 65% | Cronbach's α : 0.81–0.96; Test–retest: 0.73–0.96 | Good fit to the Rasch model: 17/22 χ^2 test: nonsignificant | |
| | Response rate: 61% 2 items >10% missing data | Cronbach's α : 0.76–0.92; Test–retest: 0.77–0.85 | 100% scaling success; low correlation with SF-36, age, gender | |
| | | Cronbach's α : 0.82 & 0.77; on subscales of satisfaction measures: 0.37–0.54; Test–retest: intraclass coefficients: 0.38–0.63 for subscale; 0.62 overall | Ceiling effect: 18.9–84.3 (lower for item 'care could be better'); all satisfaction scores discriminate for age, disease stage | |
| Originally developed in the USA [22] | Response rate: 50%; missing response (total scale): 4.2% | Cronbach's α : 0.74–0.92 | 1D or 3D structure | |
| | Response rate: 87% 95% of questionnaires with less than 50% missing responses | all Cronbach's $\alpha \geq 0.82$ except for global satisfaction = 0.74 Test–retest on 172 patients over a 1-week weighted $\kappa < 0.70$ for 24 items | One item out of 60 loaded on its and another scale; low correlation with quality of life; scores discriminated patient groups in terms of age, education, health status, problem at the communication of diagnosis; ceiling effect: 1.8–26.7% | |
| | | Cronbach's α : 0.93 total; 0.94 doctor subscale; 0.89 nurses subscale | Two factors (doctors and nurses); concurrent validity with the Medical Interview Satisfaction Scale; divergent validity with eating satisfaction | [1,59] |
| Adapted in Turkey [51] | Response rate after elimination of items with >10% missing data: 79% | Cronbach's α : total 0.99; subscale: 0.87–0.99 | Four factors explaining 80.5% variance; construction short form; skewness: 1.17–2.75 | [70] |

[†]Original psychometric study sample size.

Table 2. Description of cancer patient treatment satisfaction or satisfaction with care questionnaires.

| Instrument | Country (sample size*) | Purpose/assessment time/type of cancer | Length | Aspects of care assessed | Response options/scoring |
|--|----------------------------------|--|--|--|--|
| Worthington Chemotherapy Satisfaction Questionnaire (WCSQ) [46] | UK (n = 173) | Cancer patients perception of chemotherapy nursing care when receiving chemotherapy as a day case | 47 items | Interpersonal/technical aspects of care, patient education, multidisciplinary teamwork, treatment environment and hospital accessibility | Visual analogue scale, adjectival scale (e.g., accessible, relaxed, anxious and happy) |
| Princess Margaret Hospital Satisfaction with Doctor Questionnaire (PMH/PSQ-MD) [34,35] | Canada (n = 292; n = 149) | Cancer patients perception of interaction with doctors during radiotherapy or medical or radiation consultation follow-up | 29 items | Information exchange, interpersonal skills, empathy, quality of time by 2 factors: physician disengagement and perceived support | 5-level Likert scale; 'strongly agree' to 'strongly disagree', and 'does not apply' |
| FAMCARE-Patient scale [15] | Canada (n = 145) | Advanced-cancer patients perception of palliative care during a Phase II outpatient palliative care intervention | 16 items for patient version | Information giving, availability of care, psychological and physical care | 5-level Likert; 'very satisfied' to 'very dissatisfied' |
| Patient Quality of Care Questionnaire-End of Life (QCQ-EOL) [39] | Korea (n = 235) | Terminally ill patients perception of the quality of their care | 16 items | Dignity-conserving care, care by healthcare providers, individualized care and family relationships | 4-point Likert scale Not at all to very much |
| Cancer Patient Assessment and Reports of Excellence [40] | USA (n = 206) | Advanced cancer patients perception of quality of care; within 1–2 months of diagnosis of advanced cancer | 20-item time 1; 15 and 10 items time 2 | Communication during diagnosis, prognosis, staging work-up and communication about treatment decision making and experience with chemotherapy/radiotherapy | Reports about perceptions of quality of care: 'yes/no' or 4-level Likert scale from 'always' to 'never' |
| Comprehensive Assessment of Satisfaction with Care (CASC) [26,31] | European (n = 854) | Cancer inpatient perception of medical, nursing care and hospital services and care organisation, within 15 days of hospital discharge | 61 items | Doctors and nurses technical, information and interpersonal skills, availability, care and services organization and general satisfaction | 5-level Likert scale; from 'poor' to 'excellent', 'strongly agree' to 'strongly disagree' or 1–10 rating |
| EORTC IN-PATSAT32 [14] | International (n = 762) | Cancer inpatient perception of medical, nursing care and hospital services and care organization, within 15 days of hospital discharge | 32 items | Doctors and nurses technical, information and interpersonal skills, availability, care and services organization and general satisfaction | 5-level Likert scale; from 'poor' to 'excellent' |
| OUT-PATSAT35 [36] | France, Spain (n = 416; n = 100) | Cancer outpatient perception of medical, nursing care and radiotherapy or day-hospital services and care organisation in the course of treatment | 35 items | Doctors and nurses technical, information and interpersonal skills, availability, care and services organization and general satisfaction | 5-level Likert scale, from poor to excellent |
| Patient Satisfaction and Quality of Life In Oncological Care (PASCOQ) [37] | Germany (n = 3384) | Cancer patient satisfaction with oncological outpatient services, during outpatient treatment | 120 items | Patient–provider relationship (doctor/nurse), empathy, listening, trust, premises, interior, magazines, information and shared decision making | Report questions |

*Original psychometric study sample size.

Table 2. Description of cancer patient treatment satisfaction or satisfaction with care questionnaires (cont.).

| Translation/cultural adaptation | Evidence of acceptability | Evidence of reliability | Evidence of validity | Studies using the questionnaire |
|--|--|---|--|---------------------------------|
| | Participation rate: 77% | Cronbach's α : overall scale = 0.77 Subscales: 0.35 (hospital access)–0.92 | Comparison between compliant/noncompliant patients ($p < 0.01$ for 3 out of 4 tests) | |
| Translated/validated in French [52] | Response rate: 64% | Cronbach's α : 0.93 and 0.90 Test–retest: 0.83 and 0.73 for two factors | Excellent goodness of fit for two factors; correlated moderately with quality-of-life questionnaire | [56] |
| Family version adapted in Norwegian [53] | 1–4 items missed by up to 22% individuals | Cronbach's α : 0.94 | One factor, not correlated with performance status but with depression and anxiety | [64] |
| | Item completion rate: 97.9% | Cronbach's α : 0.73–0.89 | Four factors; subscale scores differentiate patients for clinical situation, care setting, performance status; moderate r with quality of life | |
| | Missing: 1.6–3.6% | Cronbach's α : 0.76–0.84 | Three factors; correlation item/factor: 0.37–0.47; convergent validity with mental health; criterion validity with quality of care item: 0.16–0.41 and multi-item scale: 0.43–0.60 | |
| Simultaneously developed in Belgium, France, Italy, Poland and Sweden Adapted in Greece [49] | Response rate: 73–100%; median item omission: 7% | Cronbach's $\alpha > 0.80$ | Overall scaling successes: 56 (Swedish sample) -76% | [55,58,61] |
| Psychometric testing in 9 countries and 8 languages; subsequent psychometric testing in South Asia and Spain [50,54] | Response rate: 85%; median item omission: 2% | Cronbach's α : 0.80–0.97 (except for access scale = 0.67) Similar results in Spain Test–retest: intraclass coefficient > 0.70 (except for general satisfaction scale = 0.66) | 100% scaling success; known-group comparisons effect sizes: small for 8 scales, moderate for 2 scales; ceiling effect: 6–32%, $< 15\%$ for waiting time and access; low r with QLQ-C30 | [57,63] |
| Separate psychometric testing in France and in Spain [48] | Response rate: 96%; median item omission: 4.4% $> 70\%$ items answered in Spain | Cronbach's α : 0.72–0.96; 0.60 (environment)–0.97 in Spain | 15/35 items with scaling failure; ceiling effects: 5–49% in Spain, $< 15\%$ for waiting time and environment | |
| Developed in Germany | Response rate median: 84% | Cronbach's α : 0.71–0.87 | Low correlation with quality of life | [60] |

^aOriginal psychometric study sample size.

measures of distinct concepts) validity. Despite high correlations among satisfaction subscales, there may be value in assessing different satisfaction domains depending on the purpose of the satisfaction assessment.

Different aspects of psychometric performance were less often considered, including reproducibility (i.e., test–retest reliability) or responsiveness (i.e., score change across patient groups or over time). The estimation of minimally important score differences was only determined in one study. This unveils a topic where efforts can be made in future research. Appropriate interpretation of satisfaction scores is of utmost importance, since it will support key decisions, such as treatment choice or (dis)continuation of interventions in hospitals. Methods such as cumulative response curves could be applied to satisfaction measurement. Alternative methods to support interpretation that may be appropriate for satisfaction scores should also be investigated. For instance, it has been suggested that complementing satisfaction ratings with questions that ask for ‘objective reports’ about events that did or did not happen during a clinical encounter ascertain satisfaction measures [65]. Care ratings can be used to summarize experience of care, whereas reports would capture details about healthcare experience [66]; these may be related to overall care ratings in order to pinpoint priorities for care improvement. The specific benefits of these complementary approaches need to be further ascertained.

Appropriate score variability allows for the detection of differences in satisfaction levels between patients care conditions or change in satisfaction levels over time. However, different studies did not report variability of score distribution. Patients’ satisfaction ratings are generally positively skewed, evidencing ceiling effect. Multi-item questionnaires and a range of response options (at least five) seem to allow for better score variability [18]. Evaluative (with ‘poor’ to ‘excellent’ anchors) or satisfaction rating scales appear to provide similar good psychometric properties [67]. However, diverse types of response scales were noticed among questionnaires reviewed, some with less background information on their psychometric performance. In addition, it should be noted that the use of various response scales/options in a same questionnaire may render its crosscultural adaptation complicated. Indeed, even in recommended translation procedure, subtle difference in the semantic results may be introduced across languages [68].

The comparability of measures of patient perspective across cultures and language groups has gained increased interest [23]. Clinical research in oncology often requires collaboration across countries and, thus, availability of culturally and linguistically adapted questionnaire versions. Few satisfaction-with-care questionnaires were developed at the outset in different cultures or languages [13,14]. This approach allows for the selection of issues that are relevant across cultures and for their translation into item content of equivalent meaning.

Some of the questionnaires reviewed were translated, adapted and validated in another culture/language setting [37,38,48–50,52,53]. Divergence with original psychometric results in terms of the factorial structure of the questionnaire was often observed [38,49,52,53].

However, little information is provided on the translation process or results (e.g., with regard to the need to reconcile item wording between translators or after patients’ cognitive debriefing) to explain the psychometric data obtained. Aaronson underlines the importance of soliciting feedback from local investigators regarding possible problems in questionnaire item wording [69]; this, combined with the psychometric data gained from the use of alternate language versions, can inform on further development or refinement of the original questionnaire version. In addition, the concept of patient satisfaction may differ across cultures; the components of satisfaction may not be similar in different countries or their relative importance may differ from one country to another. The very concept of patient satisfaction may not even be relevant in all cultures. Research to investigate these topics would be worthwhile to enrich the understanding of patient satisfaction and validate the measurement of this concept in an international context.

Other patient satisfaction assessment challenges were not considered in this review; these comprise of a consistent method of questionnaire administration, efforts to maximize response rate and obtain representative samples and appropriate comparisons of data adjusting for case mixes.

Five-year view

A number of cancer patient satisfaction questionnaires designed for various care contexts exist. It may, thus, be wise in the coming years to build on existing standardized tools to allow for comparisons and interpretation of satisfaction scores. However it is possible that the future will see cancer patient instruments with core satisfaction items complemented with new specific items reflecting a patient’s specific concerns and priorities in relation to new interventions or care-setting organizations.

Existing instruments may be adapted or refined for use in different cancer settings or cultures/languages. Detailed methodological recommendations should be developed for questionnaire adaptation to alternative cancer care contexts, languages or cultures. Challenges to address with greater attention in the future include the appropriate interpretation, reporting and use of patient satisfaction survey data to efficiently improve care and treatment decision making.

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Key issues

- Patient satisfaction assessment is increasingly considered as a relevant and important end point in cancer clinical research and practice.
- In total, 17 patient satisfaction instruments validated for the oncology field during the period of 1999–2009 and addressing overall healthcare services or specific treatment were reviewed according to key methodological criteria.
- Most of these instruments involved interviews with cancer patients during their treatment; these demonstrate reasonable psychometric robustness (reliability, validity, responsiveness) and acceptability in the cancer setting.
- Satisfaction measures have to be adapted to the context and purpose of each particular situation. However, different satisfaction aspects are shared in many cases. Therefore, rather than creating new tools, cancer patient satisfaction assessment should consider encompassing core/generic items complemented by new ones designed for particular cancer treatment or care experience.
- Future endeavour should address the appropriate comparison and interpretation of satisfaction data across culture/language, cancer treatment or care programs.
- Cancer patient satisfaction instruments should be applied and the data reported and used for care improvement and treatment decision making.

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