Assessment of satisfaction with cancer care: development, cross-cultural psychometric analysis and application of a comprehensive instrument
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Chapter 8

Summary and general discussion
Summary

The primary objective of this thesis concerned the elaboration and testing of a Comprehensive Assessment of Satisfaction with Care (CASC) for cancer patients.

Numerous patient satisfaction surveys are now performed in various health care settings. However, different methodological factors cast doubts on the credibility of most of these survey findings. The following pitfalls are often noticed: little evidence of the patient satisfaction instrument psychometric performance, questionnaire format or data collection procedure leading to poor response rate, or high satisfaction levels contrasting with objective reports of care deficiencies.

The development and testing of the CASC were carried out, dealing with these different methodological caveats. Its psychometric performance on target populations was considered in priority. This testing is particularly important since it indicates the extent to which the instrument that is designed measures relevant variables, and that this measurement is objective [1].

Chapter 1 presents an overview of the literature on patient satisfaction. The assessment of patient satisfaction is first situated within the context of clinical research and health care quality evaluation. The following topics are then reviewed: a) the rationale for assessing patient satisfaction; b) the purposes of this assessment; c) the meaning of patient satisfaction; and d) the components of patient satisfaction measurement. This chapter ends arguing for the development of a new cancer patient satisfaction questionnaire.

Different reasons motivated the dissemination of patient satisfaction surveys. The need for identifying effective health care interventions, accounting for patients’ viewpoint was stressed. Besides health care users’ and patients’ associations became more active and powerful in claiming for overall health care quality.

The purposes underlying the assessment of patient satisfaction consist in: 1) assessing treatment acceptability, 2) identifying sources of patients’ dissatisfaction, motives of non-compliance to treatment, 3) establishing database for benchmarking and comparative assessment. This assessment is useful in the evaluation of treatments, patterns of care, care service delivery or health care systems and may supply clinicians or health care managers with important information for improving their performance.

Presently, the meaning of ‘patient satisfaction’ is still poorly understood and the interpretation of satisfaction ratings remains confused. Different theoretical models have been proposed, involving expectations and values. However, considering the over-reported high satisfaction levels in most surveys, it was suggested that dissatisfaction be only expressed when an extreme negatively event occurs.

Various taxonomies of patient satisfaction have been elaborated depending on the context and objective of assessment. There is a consensus that measures of patient satisfaction should consist of multiple items, since a multidimensional assessment provide greater score variability and clearer indications for prioritising care improvement. These items should also be relevant to patients. Across cultures and health care settings, the importance of the care provider-patient interaction has been underscored.

The identification, in oncology, of unmet care needs and dissatisfaction emphasises the need to improve care in this setting, and so assess and monitor this endeavour. However we did not find a standardised comprehensive questionnaire that could be used for assessing patient satisfaction in the oncology hospital.

Chapter 2 reports on the initial development of a comprehensive questionnaire (CASC) for assessing cancer patients’ perception of the quality of care received in the oncology hospital. The provisional version of the CASC includes 61 items assessing doctors’ and nurses’ technical
competence, communication skills, interpersonal qualities, availability; aspects of the hospital environment and treatment planning; and general satisfaction. Most items refer to an aspect of care rated on a 5-point Likert scale from "poor" to "excellent". This scale is reported to provide greater score variability. Additionally, each aspect of care is also evaluated by a dichotomous (yes/no) question on the patient's wish (or not) for its improvement.

This questionnaire resulted from consecutive pilot tests (from April 1994 to September 1995). Amendments of the CASC items were based on patients' comments, items' omission, and variability of score distributions. Items showing low scores or acceptable score distributions were stressed as appropriate for inclusion in the revised questionnaire version.

Chapter 3 presents the results of a study aimed at defining the structure of the CASC revised version, and at assessing the internal consistency, convergent and discriminant validity of its scales. Three hundred and ninety-five consecutive cancer patients discharged from an oncology institute in Italy were asked to complete the CASC at home and return it in a self-addressed envelope. Two percent of the patients refused to participate and 25% did not return the questionnaire. Separate factor analyses of the CASC sub-scales disclosed the perceived extent of doctors' and nurses' availability, coordination, human quality, technical competence, provision of psychosocial care and information, as well as the patients' general satisfaction, perception of the organisation of care, access and comfort. Multi-trait scaling analysis was carried out on item-grouping resulting from factor analyses. High levels of internal consistency and convergent validity were obtained but discriminant validity could be improved.

Results of this psychometric testing of the CASC forecasted adequate properties that had to be confirmed by repeating these analyses in a cross-cultural setting.

Chapter 4 addresses the cross-cultural psychometric properties of the CASC. The study reported assessed whether equivalent scaling properties could be found in the CASC administered in cancer patients from French, Polish and Swedish oncology settings, in comparison to the scaling properties previously evidenced in the CASC with the Italian sample.

One hundred and forty, 186 and 133 oncology patients were approached in France, Poland and Sweden, respectively.

Multitrait scaling analysis on an item-grouping adapted for the French, Polish, Swedish and Italian samples together, provided excellent internal consistencies and convergent validity estimates. Discriminant validity proved satisfactory for most of the CASC scales. Psychometric analyses of the CASC across four countries of the main European regions revealed that patients distinguished similar dimensions of care. These may be validly assessed using the revised scales of the CASC.

Chapter 5 reports on a cross-cultural comparison of the CASC response scales. We investigated what proportion of patients wanted care improvement for the same level of satisfaction across samples from oncology settings in France, Italy, Poland and Sweden, and whether age, gender, education level and type of items affected the relationships found. To complete the CASC, patients were invited to rate aspects of care and to mention, for each of these aspects, whether they would want improvement. One hundred and forty, 395, 186 and 133 oncology patients were approached in France, Italy, Poland and Sweden, respectively.

Across country settings, an increasing percentage of patients wanted care improvement for decreasing levels of satisfaction. However compared to the other countries, in France a higher percentage of patients wanted care improvement for a high satisfaction ratings, and also compared to other countries, in Poland a lower percentage of patients wanted care improvement for low satisfaction ratings. Age and education level had a similar effect across countries: older patients and patients with lower education level wanted care improvement less frequently.

Confronting levels of satisfaction with desire for care improvement appeared useful in highlighting the different implications of satisfaction ratings across oncology settings from countries. Linguistic or socio-cultural differences were suggested for explaining these discrepancies.
Chapter 6 describes a study aimed at evaluating the feasibility of conducting a patient satisfaction survey in the oncology hospital setting, using the CASC completed by patients at home.

Socio-demographic and clinical data were collected for 133 consecutive patients. Patients were asked to complete the European Organisation for Research and Treatment of Cancer QLQ-C30 (version 2.0) just before hospital discharge and the CASC at home two weeks after discharge.

Respondents (73% of patients approached) were younger, hospitalised for a shorter time and presented less appetite loss, nausea and vomiting, and better physical and role functioning than non-responders. Aspects of care for which patients wanted most improvement were associated with the provision of medical information. In multivariate analyses, longer hospital stay was associated with higher satisfaction with all aspects of medical and nursing care. This unexpected relationship between satisfaction with care and length of hospital stay was probably due to the fact that in the institute where the study took place, early discharged patients were not assured of care continuity and lacked of information for self-care at home. Higher global quality of life was associated with higher satisfaction with all aspects of care.

We concluded that conducting a patient satisfaction survey in an oncology hospital setting proved feasible, however further survey should attempt at obtaining the opinion of patients in more severe physical conditions. The assessment of patients' satisfaction provided indications for care improvement, which specifically pertain to the particular hospital were the patient satisfaction survey was conducted. Although the results of this study are specific to one hospital, the methods could be reproduced in other hospital settings, but might possibly lead to other conclusions.

Chapter 7 presents a study comparing the performance of the CASC according to the timing of questionnaire administration. Comparisons were made in terms of: a) the completeness and representativeness of the data set (number of missing questionnaires, number missing item responses, respondents' representativeness to the target population); b) the questionnaire acceptability to respondents (time and difficulty to complete); c) the questionnaire reliability; and d) variability of scores.

One hundred and ten consecutive breast cancer patients hospitalised for surgery were randomised between being sent the CASC at 2 weeks (T2W) or at 3 months (T3M) after hospital discharge. The time to complete the CASC was shorter at T3M than at T2W and the mean percentage of item omission was lower at T3M (1.68) than at T2W (3.82). However the response rate was much higher at T2W (87%) than at T3M (66%), making item omission non significant. At both times of questionnaire administration samples encompassed a greater number of patients having undergone a less invasive surgery. Besides, the multi-item scales of the CASC demonstrated adequate internal consistency coefficients, except the general satisfaction scale at T3M, and fairly symmetrical distribution of scores.

It was concluded that priority should be devoted to obtaining a high response rate to the questionnaire. Hence, administration of the CASC shortly after discharge should be the favoured working option. Our results underlined that cancer patients' perception of care may vary in a 6 weeks time lapse. Therefore, the timing of assessment needs to be clearly specified in cancer patients' satisfaction survey.
General discussion

In this thesis, we reported studies related to the development and validation across countries, of a comprehensive questionnaire for assessing cancer patients’ perception of the quality of care provided in hospital. The feasibility of using this questionnaire in the routine delivery of care, as well as the optimal timing for administering this questionnaire was also tested.

In the sections below, key findings as well as limitations of these studies will be addressed. More specifically, the following topics will be considered: methodological issues, further research needs and implications for practice.

Methodological issues

The CASC was elaborated paying particular attention to: 1) its content validity, 2) the variability of its score distributions, and 3) its acceptability to patients. So its development followed several requirements.

Firstly, the relevance of issues selected for inclusion in the CASC, was explored through interviews with both oncology specialists and cancer patients. Since the CASC is expected to assess patients’ subjective perception of care quality, its validity depends on whether patients have contributed to the determination of its content, by expressing their views on which aspects of care are important for quality of care.

Secondly, to maximise the discriminative power of the CASC scales and the variability of patients’ responses, we chose to design a multidimensional questionnaire addressing detailed and specific aspects of care [2] and to use a response scale showing greater response variability [3].

Thirdly to enhance the practical usefulness of this instrument in terms of prioritising care improvement from patients’ viewpoint, for all aspects of care evaluated, we added to the first question asking patients to rate his/her level of satisfaction, a second question inquiring on his/her desire or not for improvement.

Fourthly, to ensure acceptability to patients and so, maximise response rate and completeness of data, repeated pilot tests of the questionnaire phrasing were performed. Moreover the questionnaire length was determined balancing requirement for comprehensiveness and burden on patient. For application across country languages, the CASC was translated and adapted according to standardised guidelines [4]. With regard to the conduct of the survey, in order to minimise the social desirability artefact, the confidentiality of respondents’ answers and the neutrality of the person gathering the data was stressed [5]. Besides patients were asked to complete the questionnaire at home; this was also expected to elicit more frank expression of patients’ viewpoint than in the place where they received care.

Different factors raise doubts on the credibility of most current satisfaction survey findings. These surveys rarely report their response rate [6], which prejudices the generalisability of their results. Besides high satisfaction levels are generally evidenced, contrasting with objective reports of care deficiencies. Of utmost importance, most of these surveys rely on questionnaires that demonstrate little evidence of psychometric performance [7].

In contrast, the different studies reported on the CASC substantiated the feasibility, reliability, validity and usefulness of this questionnaire in the oncology hospital setting. Its administration proved acceptable to patients, evidencing high rates of study participation, overall response, and individual item answer. Moreover the procedure for collecting the CASC data proved feasible in the routine
delivery of care. Hospital managers promoted the project by funding the personal required, and the survey was well-accepted by clinicians. The CASC evidenced acceptable variability in score distributions, resulting in the identification of specific aspects of care that needed improvement. Additionally, analysis of reliability and, convergent and divergent validity of the CASC scales demonstrated acceptable to excellent estimates, highlighting patients’ ability to discriminate between care dimensions, across samples from different European countries. Amendments of the CASC were suggested to enhance discriminant validity.

Further research needs

The different studies reported in this thesis provided information on the strengths of the CASC but also on its limits. These latter indicate areas for further research.

Firstly, considering the size of each country/language samples, estimates of the CASC reliability, and convergent and discriminant validity should be regarded cautiously. According to Tabachnik et al. [8], multivariate analysis requires 5 to 10 observations per variable to obtain stable estimates. Since we performed multi-trait scaling analyses independently in the four country samples we should have recruited at least 300 patients by participating setting. Repeating these analyses on larger samples is thus required. Moreover to increase the generalisability of the results, optimally these analyses should be carried out in a greater number of institutions by country.

Secondly, patients’ characteristics (e.g.: age, education, personality, mood, previous care experience, expectations), and socio-psychological artefacts (e.g.: social desirability, fear of unfavourable treatment, gratitude) on the one hand, and aspects of care (e.g.: technical quality of care, interpersonal manner, accessibility, costs, efficacy, continuity, environment, availability) on the other hand, have been shown to influence satisfaction ratings [9-11]. The interpretation of satisfaction ratings is not straightforward and the relationship between satisfaction ratings and quality of care is complex [12]. Moreover little is known on the implications of satisfaction ratings in terms of care improvement. As noted by Cleary [13], knowing whether satisfaction is “more a function of what is done for the patient than a function of the kind of patient being treated” has decisive implications for care improvement. Different proposals have been expressed for clarifying the interpretation of satisfaction with care data. To further understand the respective role of satisfaction ratings determinants, a number of authors have suggested the use of qualitative methodologies and the focalisation on negative experiences of care [14,15]. Moreover, there is an increasing emphasis on complementing satisfaction ratings by questions that ask for “objective reports” about events that did or did not happen during a clinical encounter (e.g.: referring to practice guidelines). Such questions are both more interpretable and actionable for quality improvement purposes [16]. Qualitative methodologies and objective care reports may provide another perspective on the high satisfaction ratings commonly reported in surveys.

Thirdly, quality of life is an important target of care provision in oncology (e.g.: relieving symptoms). Whether patients are satisfied with interventions aimed at improving their quality of life (or attenuating the burden of illness and treatment on quality of life) should thus be checked. Different studies evidenced that patients with poorer health, either emotionally or physically, tend to be less satisfied with their medical care [17]. Also, in chronically ill patients, when controlled for other patients’ characteristics, poor overall health predicted less positive judgement of care in the context of general practice [18]. In the study reported in chapter 6, higher global quality of life was associated with higher satisfaction with care. However the design of the study, which did not include a repeated measure of quality of life, did not allow for determining whether patients expressed higher levels of satisfaction as a result of enhancement of their quality of life. Moreover some aspects of quality of life presented an unexpected correlation with patient satisfaction, which should be further explained: patients who reported poorer physical functioning expressed higher levels of satisfaction with care.
Fourthly, it should be noted that in order to interpret satisfaction data across settings, the procedure for data collection (i.e.: moment and place of questionnaire completion) should be homogeneous. For example in the cross-cultural studies reported in chapter 4 and 5, patient satisfaction data were collected either by a research assistant, a nurse or a doctor, and either in the hospital or in the patient’s home. As a result, the interpretation of satisfaction data across languages and cultures could be attributed not only to linguistic factors and differences in patients’ expectations across health care systems but also to the heterogeneity of the study methodology.

Fifthly, the CASC criterion or predictive validity were not assessed in the present work. Validity testing aims at determining whether or not the findings reflect reality. Criterion validity is the correlation of the new scale with some other measure of the trait under study, ideally an existing ‘gold standard’ which is well accepted in the field [7]. If the two measures are administered at the same time, this is referred to as concurrent validity. If the criterion is not available until some time in the future, this is called predictive validity. With regard to patient satisfaction it is difficult to find a commonly accepted ‘gold standard’. Usually, satisfaction ratings are compared with a patient’s behaviour hypothesised to reflect dissatisfaction. For example, in a recent study, the validity of a questionnaire to assess patient satisfaction with chemotherapy nursing care was tested comparing satisfaction ratings with patients’ compliance [1]. Other such criteria have been proposed, for example: changing health care service, registering a letter of grievance or initiating a malpractice suit. However, across cultural settings it is difficult to determine a specific pattern of patient’s behaviour that represents dissatisfaction. Changing health care service may not be possible in any geographical area, and registering a letter of grievance or initiating a malpractice suit may not be an accepted practice across health care systems. An alternative approach to assess the criterion validity of the CASC could be the comparison of a self-reported versus an interview administration of the CASC, in terms of patients’ responses. As reported by Williams [19], patients often display a more critical viewpoint when given the opportunity, through more open ended questions, to express themselves in their own terms. Interview responses might thus be considered as the ‘gold standard’. As patient satisfaction questionnaires usually result in high satisfaction ratings, a comparison between data collected from a self-reported questionnaire or from a semi-structured interview could provide indications on the degree to which the CASC self-report questionnaire elicits answers that approach what patients may more freely express in the framework of an interview.

Implications for practice

The development and cross-cultural psychometric testing of the CASC is meant to provide a psychometrically robust instrument for use in multicentre clinical research or in health care services evaluation. The studies reported in this thesis provide information on the strength and limits of the CASC, and indications for its amendment and further analyses. Larger sample sizes, increased number of participating institutions, complementary qualitative analyses or “objective reports” of care events, and analysis of criterion validity should be further considered, paying particular attention to homogenise the procedure for data collection.

The CASC raises patients’ opinion with regard to the quality of hospital doctors’ and nurses’ availability, technical, interpersonal skills, information provision as well as to hospital access, comfort, care organisation and general satisfaction. On the strength of appropriate psychometric properties, this questionnaire may serve different purposes. Firstly, it may be used in patient satisfaction surveys for institutional purposes. In that context, thanks to the assessment of multiple aspects of care, the CASC allows for contrasting ratings of satisfaction provided by patients to a comprehensive list of care aspects relevant to the oncology hospital context. Scores of the CASC scales may be compared across hospital departments to establish the desired level of satisfaction, with the level in a given department then checked against the mean level of satisfaction within the hospital.
at large. The implications of these ratings may also be evidenced in terms of patients’ desire for care improvement. Still at the institutional level, recording satisfaction with care scores over time allows for assessing the impact of initiatives to stimulate improvement. Secondly, in cross-setting clinical research, an assessment of patient satisfaction with care may convey useful information about a specific quality of life issue. In that context, an evaluation of satisfaction with care is a further endpoint for judging the efficacy of treatment. This measure may also provide indication on factors that influence patients’ willingness to undergo or sustain treatment. Used in cross-cultural comparative health care research, the CASC could provide a better understanding of satisfaction with care according to patients’ cultural characteristics.

Conclusion

Across countries, patients’ views on the care received has been increasingly considered as a valid endpoint for assessing and monitoring the quality of health care. Surveying patient satisfaction is now widely performed. However the methodology applied for these surveys have often demonstrated shortcomings, cautioning the accuracy of their results. Efforts to develop valid and reliable methods for assessing patient satisfaction have emerged very recently and their diffusion across countries is still limited.

The need for care improvement may be particularly relevant in the field of oncology. Cancer patients are often facing lengthy treatment and continued dependence on health care providers. Dissatisfaction with care has often been reported, especially with regard to the interaction with health care providers and care organisation.

The present work aimed at developing and testing across cultural contexts a questionnaire for assessing cancer patients’ perception of the care provided in hospital. It was meant to supply organisations wishing to enhance care in oncology, with a psychometrically robust instrument for monitoring their endeavour. It is our hope that future use of the CASC will be profitable to the improvement of the quality of care provided to cancer patients.

References


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