

Original article

Assessment of hospitalised cancer patients' needs by the Needs Evaluation Questionnaire

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Summary

Background: Cancer disease modifies the order and the nature of needs connected with the state of health. The aim of this study was to evaluate the informative, psychological, social and practical needs of hospitalised cancer patients by means of the Needs Evaluation Questionnaire (NEQ), an instrument designed concisely for the convenience of patients and medical staff.

Patients and methods: Different samples of consecutive hospitalised cancer patients were involved in the various phases of designing the instrument: 30 patients for items identification, 101 patients for completeness and acceptability evaluation, 423 patients for construct validity and prevalence of needs; content and reliability analysis were performed on 2 subsamples of, respectively, 60 and 88 of the patients from the last sample.

Results: The validation analysis showed rather good reliabil-

ity, structure validity and internal consistency of the questionnaire. The prevalence analysis showed that the most common needs were: 'more information about my future conditions' (74%); 'more information about my diagnosis' (56%); 'more information about the exams I am undergoing' (52%); 'more explanations on treatments' (51%); 'to have a better dialogue with clinicians' (57%); 'better services from the hospital' (bathrooms, meals, cleaning) (56%).

Conclusions: The NEQ, self-completed by patients, has proven to be a useful clinical tool for obtaining a systematic and undistorted overview of the principal needs with respect to the state of health of patients. This instrument, which can also be administered by persons not belonging to the health care system such as volunteers, and inserted into the patients' hospital charts, could be used by the medical staff to identify the real needs of patients at an early stage.

Key words: cancer patients, needs assessment, questionnaire

Introduction

Cancer disease modifies the order and nature of needs (in the sense of subjective desire and a lack of something necessary) connected with the state of health. The evolution of the disease, and the continuous controls and therapeutic treatments can greatly influence some aspects of daily life, since they alter relationships with family members and friends, diminish working capacity and leisure activities, modify the patient's social role and threaten his confidence.

Analysis of the literature points out that the needs of the cancer patient have different 'nuances' and different 'weights' according to the situation he is experiencing (hospitalisation, home treatment, first diagnosis phase, etc.). Moreover, particular conditions are associated with specific need categories: practical and physiological needs were reported principally when the patient returned home [1–8]. It was observed that the patients tend mainly to report unsatisfied needs when the disease or the treatment cause restrictions to their daily activities, in particular when their financial resources have been reduced so that they are compelled to ask for medical and public assistance and when they are assisted

by people not belonging to their own families [9]. The informative needs are mainly recognised during the diagnostic and decisional phase before treatment [10–12], and when patients must undergo invasive surgical treatments or medical treatments with important side effects that cause a change in their life style as well as a modified image of their body [13–19]. The need of psychosocial support appears more often when the patient perceives the situation difficult to control for physical or emotional reasons [20–26].

Regarding needs assessment, it is important to make a subjective survey, that is, to report the needs expressed directly by the patient. This arises from observation of a discrepancy between the needs perception of staff and patients. It was observed that the nurses tended to attribute to the patient needs primarily of a psychological origin, overestimating their anxiety, hostility and depression levels, while the patients tended to highlight needs of physical origin. Moreover, a difference in perception of dissatisfaction concerning personal hygiene, diet, defecation, activities and rest was noted. In general, patients perceived major deficiencies for needs categories that included physical problems, while nurses underscored mainly psycho-social problems [6, 27].

We believe that the use of a self-completed questionnaire should help in the clinical encounter to obtain a systematic and undistorted view of the principal needs linked to the state of health of the patient. This instrument, administered by non-members of the health care system such as volunteers, and inserted into the patients' hospital charts, could be used by the medical staff to identify at an early stage the patients' real needs. This modality of needs collection acknowledges the central position of the patient with respect to his condition of disease and aims to increase the patient's opportunities to express his own requirements and his own discomfort.

On the basis of these considerations, in 1997 a new project was begun which aimed at analysing and evaluating the needs expressed by hospitalised cancer patients and which led to realisation of the instrument which is the object of this study.

Patients and methods

The Needs Evaluation Questionnaire (NEQ) design

The first NEQ design phase was based on semi-structured encounters with 30 patients, interviewed individually by one of the investigators (L. Gangeri) in order to determine their needs relative to the condition of being ill and in a hospital.

During the interview each patient was asked to signal his primary needs arising from the disease and his hospitalisation. The encounter continued with more precise questions as to whether the patient felt he had informative, psychological, and social needs according to the four sub-areas recognised by the literature as the principal categories of need.

From the encounters with the 30 patients, a list of 75 needs emerged that was afterwards analysed in order to eliminate certain needs not connected with the state of health (i.e., the need for a vacation) and those considered as constants (i.e., the need for recovery, the need for returning home soon, the need for not having complications after surgical treatment).

The result of this analysis was 28 verbal expressions that indicated the needs required to constitute the basis for the first version of the questionnaire.

Furthermore, when asking patients to graduate their needs on a four-point verbal Likert scale (not at all/a little/much/very much), many of them indicated a difficulty in graduating the level of their needs, so that we chose a simpler 'yes' vs. 'no' response scale.

NEQ comprehensibility and acceptability

The first version of the questionnaire was administered to a group of 101 hospitalised patients by the Division of Cancer Surgery of the National Cancer Institute in Milan to evaluate its comprehensibility, completeness and acceptability for the patient. The administration of the questionnaire was carried out by five volunteers from the League against Cancer after they had received appropriate instruction on the subject. The volunteers were required to contact patients who had been in the hospital for at least three days, to explain the reason why the patients were asked to complete the questionnaire, obtain their verbal consent and distribute the questionnaire. This first version of the questionnaire ended with two open questions: the first one asked the patient to list any further need that was not contained in it while the second asked the patient to indicate the need that he considered the most important.

For patients with practical difficulties (illiteracy, functional defects) a volunteer helped with the autonomous completion, reading the ques-

tions and then recording the relative answers. In this phase the feasibility of a procedure for the systematic survey in a ward was evaluated.

Information relative to further difficulties in completing the questionnaire was registered, as well as the time of completion and the necessity of being helped or not by a member of the patient's family or by a volunteer.

The results of this phase have not shown problems related to comprehensibility and acceptability: a median completion time of five minutes was required and 63% of the patients declared that they had been pleased with the questionnaire.

Three further items were eliminated. Two of them: 'I need to maintain fully my activity' and 'I need not to feel dependent on others' were recognised as obvious and taken for granted. The third one 'I need to be more in contact with my family doctor' was eliminated because it could not be satisfied inside the hospital.

This second version of the questionnaire, consisting of 25 items, was administered by the same procedures as the previous phases to a sample of 392 patients who were in the same surgical ward.

Content analysis

A subsample ($n = 60$) of the 392 patients was interviewed to verify the meaning attributed to certain verbal expressions of the questionnaire that were unclear or ambiguous. The six identified verbal expressions were: 'future conditions', 'sincere clinicians', 'intimacy', 'commiserated', 'reassured' and 'involved'. During the interview each patient was asked to specify the meaning of each of them. The free answers were written down and then classified, by investigators who had not conducted the previous interview, into a grid made of classes of different meanings.

Reliability

The NEQ was then administered a second time within a week of the first evaluation to another subsample of 88 patients to study the instrument reliability; patients were informed about the aim of the second administration and were told not to try to remember the answers given on the first occasion; to further avoid recall bias, the order of the questions in the second administration was changed. The reliability of each item was evaluated by means of Cohen's Kappa [28] index on the subsample of repeated measures. Conventionally, values of Kappa lower than 0.4 indicate a poor reliability, from 0.4–0.6 moderate, from 0.6–0.8 substantial and from 0.8–1 almost perfect reliability [29].

Needs' prevalence and structure validity

The NEQ (first and second versions) was administered to a total of 493 patients; the evaluation was considered valid if <5 items of the questionnaire were missing. The compilations of 70 subjects did not meet this requirement and they were therefore excluded from the analysis of needs prevalence and of construct validity. For both analyses only the 25 items in the first and in the second versions were considered.

To evaluate the validity of the hypothesised structure (construct validity) of the NEQ we investigated whether the individual items in the questionnaire could be synthesised into a smaller set of 'a priori' defined latent dimensions accounting for the intercorrelation of the observed variables. The latent structure was studied by means of confirmatory factor analysis (CFA) on the tetracoric correlations among the observed variables: the estimation of the model parameters was obtained by means of WLS (weighted least squares) method using the programme Lisrel 8 [30]. Different models have been compared through several indicators of goodness of fit to the data. Each of these indices assumes a different rationale and stresses different criteria for model evaluation.

The *chi-square statistic* [31] which indicates the absolute lack of fit of the model; contrary to conventional significance paradigms, large

values of χ^2 , and small P -values, indicate poor fit and model performance, leading to rejection of the hypothesis that the assumed model is 'true'.

The *Adjusted Goodness of Fit Index (AGFI)* [32] which, contrary to χ^2 , does not depend on sample size and measures how much better the model fits as compared to no model at all; it should lie between zero and one, large values being associated with good models.

The *root mean squared residual (RMR)* which is an index of the size of the residuals obtained by subtracting the reproduced variance/covariance matrix from the observed variance/covariance matrix.

The range of the *Squared Multiple Correlations (SMC)* [30] for each of the observed variables in the model; each index shows how well an observed variable serves as measurement instrument for the latent variable, with large values (range 0–1) being associated with good fit.

Cronbach's alpha index [33] was then calculated to estimate the internal consistency of the scales which emerged from the factor analysis.

Results

Content analysis

The classification of the open answers showed that for the majority (72%) of interviewees the term 'future conditions' (present in item 2) had the meaning of 'future physical condition'. Only for a minority did it mean 'recovery' (15%), 'quality of global life' (10%) or 'psychological condition' (3%).

Regarding the term 'sincere clinicians' (item 7) the meaning was for 97% of the respondents 'not telling lies'. Only 3% thought it meant 'more empathy'.

The word 'intimacy' (item 13) for 68% of the patients referred both to the physical sphere and psychological sphere. Only for some subjects did it refer to the physical sphere alone (25%) or the psychological sphere alone (7%).

The term 'commiserated' (item 25) was associated for 97% of cases with the concept of pity, i.e., patients showed their need for those assisting them not to evoke sentiments of pity.

As for the expression 'reassured' (item 15), this word was not tied to the need of 'emotive nearness' (12%) nor to one of 'better explanation and information' (17%), rather it seemed to express the need to 'know that the situation is under control' (72%).

The word 'involved' (present in items 5 and 10) was attributed three diverse meanings by patients, distributed in almost equal percentages: 'being informed' (38%), 'taking part in decisions' (32%), 'being listened to and considered' (30%).

Needs' prevalence

The study sample was made up of 423 patients (86% of compliance), most of whom were women (74%) with a median age of 56 years; the three most common primary tumour sites were colon-rectum (27%), genito-urinary tract (27%) and breast (22%). Table 1 shows the percentage frequencies of positive answer and of missing value for each item from 423 patients. As can be seen, some items such as 9, 10, 12, 18, 19 and 20 show a very low

Table 1 NEQ answers, distribution of missing data and reliability coefficients for each item.

Item number	Item text	Yes (%)	Missing data (%)	Cohen's K Index (88 patients)
1	I need more information about my diagnosis	56	1	0.65
2	I need more information about my future condition	74	0	0.76
3	I need more information about the exams I am undergoing	52	1	0.54
4	I need more explanations of treatments	51	2	0.58
5	I need to be more involved in the therapeutic choices	37	1	0.61
6	I need clinicians and nurses to give me more comprehensible information	39	1	0.72
7	I need clinicians to be more sincere with me	37	2	0.69
8	I need to have a better dialogue with clinicians	57	1	0.69
9 ^a	I need to receive less information on my illness (diagnosis, treatments, evolution)	10	1	0.25
10 ^a	I need to be less involved in therapeutic decisions	14	2	0.02
11	I need my symptoms (pain, nausea, insomnia, etc.) to be better controlled	33	2	0.64
12	I need more help with eating, dressing, and going to the bathroom	7	1	0.82
13	I need better respect for my intimacy	23	3	0.66
14	I need better attention from nurses	16	1	0.63
15	I need to be more reassured by the clinicians	43	2	0.72
16	I need better services from the hospital (bathrooms, meals, cleaning)	56	1	0.71
17	I need to have more economic-insurance information (tickets, invalidity, etc.) In relation to my illness	47	1	0.69
18	I need economic help	13	2	0.74
19	I need to speak with a psychologist	11	1	0.72
20	I need to speak with a spiritual advisor	12	1	0.46
21	I need to speak with people who have this same experience	38	1	0.62
22	I need to be more reassured by my relatives	21	0	0.64
23	I need to feel more useful within my family	46	1	0.93
24	I need to feel less abandoned	23	1	0.54
25	I need to receive less commiseration from other people	29	1	0.66

^a Item eliminated successively.

percentage of YES answers (less than 15%) which suggests a low prevalence of such needs in the population of oncological in-patients. The percentages of missing values for each item are very low (range from 0%–3%), indicating a good comprehensibility and acceptability of the questionnaire by the responders.

Table 2. Goodness of fit indices for the four factor models.

Models	χ^2 (<i>P</i>)	AGFI	RMR	Range SMCs
Model 1	99.7 (0.025)	0.98	0.130	0.59–0.97
Model 2	76.1 (0.290)	0.98	0.097	0.59–0.96
Model 3	45.5 (0.280)	0.98	0.077	0.67–0.96
Model 4	35.1 (0.605)	0.99	0.059	0.63–0.99

Abbreviations: χ^2 – chi square goodness of fit test (*P* = significance of χ^2); AGFI – adjusted goodness of fit index; RMR – root mean squared residual; range SMCs – range of the squared multiple correlations.

Reliability

The subsample of patients to whom the test-retest was administered was made up of 88 patients and results of the reliability analysis are reported in Table 1. The questionnaire on the whole showed a rather good reliability, with a substantial to almost perfect agreement for 19 items and a moderate agreement only for 4 items (3, 4, 20, 24). Items 9 and 10 showed too little reliability and were eliminated from the definitive version of the questionnaire.

Construct validity

In analysing the construct validity of the 423 valid questionnaires collected we followed a model generating approach with an initially specified model in which re-specification after testing is theory- and data-driven.

The initial model foresaw an information-communication factor (items from 1–10), an assistance-care factor (items 11, 12, 14, 15) and a relational factor (items from 22–25) while all the remaining ones constituted single item factors, most of them regarding a potential operative intervention. After eliminating items 9 and 10 as already described before, we concentrated on the study of the items which were hypothesised to be related to informative-communication, assistance and relational dimensions being the structure of the first model tested (Model 1). As shown in Table 2, CFA results indicated that Model 1 does not fit the data well (the model is rejected because of the low χ^2 *P*-value and the high RMR).

An accurate examination of the residuals and of the modification indexes of the preceding model made us decide to split the informative-communication factor into two: an informative one (items from 1–4) and a communicative one (items from 5–8) and to permit item 15 to load onto the communicative factor too (as well as onto the curing factor) (Model 2).

These modifications led to a relevant improvement in the model fit ($P\chi^2 = 0.29$) despite the fact that the results of the residual pattern were unsatisfactory (RMR = 0.097), indicating that the estimated covariance pattern associated with item 15 and assistance-care factor was not well accounted for by the model as occurred for item 25 and the relational factor.

Table 3. Standardized Lisrel estimated factor loadings for Model 4.

Item number	Informative first ^a factor	Informative second ^b factor	Communicative factor	Relational factor
1	0.98	–	–	–
2	0.87	–	–	–
3	–	1.00	–	–
4	–	0.89	–	–
5	–	–	0.79	–
6	–	–	0.96	–
7	–	–	0.92	–
8	–	–	0.88	–
22	–	–	–	0.89
23	–	–	–	0.82
24	–	–	–	0.84

^a Informative needs about diagnosis and prognosis

^b Informative needs about exams and treatments.

Considering a model without items 11, 14, 15 and 25 (Model 3) and treating them as single factor scales, the fit improved as expected ($P\chi^2 = 0.28$ and RMR = 0.077); examination of the residuals of this last model also made us decide to split the informative factor again into two: informative about diagnosis-prognosis (items 1 and 2) and informative exam-treatments (items 3 and 4) (Model 4); Model 4 shows a good fit ($P\chi^2 = 0.60$) and a rather acceptable residual pattern (RMR = 0.059). Table 3 shows the standardised Lisrel estimated factor loadings of Model 4; all loadings are significantly different from zero at $P < 0.001$.

Table 4 shows the estimated correlations among hypothesised latent unobserved factors by confirmatory factor analysis. As expected the correlations between informative and communicative factors are very high while the relational factor results correlate less with the others. Cronbach's alphas for factors emerged show acceptable to good levels of internal consistency.

Discussion

The first aim of this study was to evaluate the psychometric properties of a new instrument for needs evaluation on a consistent sample of 493 hospitalised cancer patients.

The high total compliance rate, the short completion time and the absence of related problems of comprehension, indicate that the questionnaire on the whole was well accepted by the patients.

The results of the test-retest procedure revealed an overall high level of reliability except for items 9 and 10; these items, which had been introduced in the questionnaire to evaluate the patients' willingness not to be involved in the treatment process, had instead showed low prevalence and reliability, possibly due also to a difficulty of comprehension typical of negative questions. The above two items have been eliminated from the definitive version of the NEQ (23 items) presently in use at the National Cancer Institute in Milan.

Table 4. Estimated correlations among hypothesised latent unobserved factors by confirmatory factor analysis of internal consistency coefficients.

Latent factors	Informative first ^a factor	Informative second ^b factor	Communicative factor	Relational factor
Informative first ^a factor	1.00			
Informative second ^b factor	0.91	1.00		
Communicative factor	0.88	0.84	1.00	
Relational factor	0.49	0.45	0.50	1.00
Cronbach's alpha	0.72	0.79	0.81	0.69

^a Informative about diagnosis and prognosis

^b Informative about exams and treatments.

The NEQ has been conceived as an aid in clinical encounters in that it systematically gathers information regarding the needs of hospitalised cancer patients. On a theoretical basis it was hypothesised that some of the items would behave as components of specific need factors (the need for information, communication, care, human relationship). Factorial analysis confirmed only in part the hypothesised structure. On the other hand the fact that most of the NEQ items behave within a unidimensional scale is consistent with the aim of the questionnaire, which is not to attribute a global point system to the patients' need state. Rather it reveals the presence/absence of differential needs, which will then be closely examined within the context of the clinical relationship for obtaining operative and adequate responses.

It's interesting to underscore the behaviour of item 15 (need to be more reassured by the clinicians) which tends, but fails, to load both onto the communicative and the assistance-care factors; in fact, from what emerges from the content analysis, patients perceived the word 'reassured' as a dimension distinct from the two factors before.

The *needs prevalence* which emerged in this study emphasises firstly how the need to have as much information as possible about one's own disease condition – especially regarding diagnosis, prognosis, exams and treatments (56%, 74%, 52%, and 51%, respectively) – is still present today in the first disease stages of hospitalised cancer patients. This is in agreement with what has also emerged in recent studies on the subject, which have underlined the demand, on behalf of patients, to receive the best possible information from doctors, recognising, furthermore, that adequate information represents an important care component for the patient [12, 34–39].

The role of the patient in the management of disease has changed with time. In this study most patients asked to have dialogues with their own doctors (57%); this can be interpreted as representing a desire for access, during a moment of calm, to means for obtaining information, and expression of a willingness to participate, in this relatively easy manner, in the decisions regarding their

own health. In order to satisfy this desire, communication with the patient must be clear, it must respect the cultural background and comprehensive ability of the patient, and take into account his or her desire to take part more or less actively in the management of the disease [12, 38, 40]. The more the doctor is able to communicate and help patients to understand key information about their condition, the more patients will perceive their care as of high quality [41].

A high percentage of patients (43%), according to data from this study, asked if they could be reassured to a high degree by doctors. On the basis of the content analysis the moment of reassurance is considered one in which the doctor in various ways makes the patient feel that the disease condition is under control.

What also seems important is the need to receive solid information regarding finance and insurance (47%). Because of the functional limits caused by the diseases themselves and their treatments, patients are often forced to abandon their work engagements, thereby creating significant consequences regarding finance and repercussions on quality of life. Many patients have also experienced a need to feel more useful within their own family unit (46%).

It is interesting to note, in closing, the low percentage of dissatisfaction with nursing assistance (< 20%, see items 12 and 14) even if rendered under unsatisfactory conditions of accommodation (56%).

The *systematic assessment* of patients' needs through the use of a simple-to-complete questionnaire meets two important demands: firstly, it is able to give patients the chance to point out their unsatisfied needs to hospital staff, and secondly, it provides important information for doctors and other health workers.

Doctors and nurses do not always know all there is to know about their patients. In most cases knowledge of the patients' conditions is limited to single aspects such as the presence or absence of certain physical symptoms which are often connected to the treatment patients have to undergo. This is, in part, connected to the hospital staff's conviction that they should intervene only for the above said symptoms in their search for possible solutions, while ignoring many other discomforts which could be more important for patients.

Among these are psychological problems connected to the disease condition with which hospital staff, often through lack of training, feel unable to cope. However, these problems could be dealt with by establishment of a procedure for informing patients of the possible existence of patient support services.

On the other hand, physical symptoms can also be undervalued or ignored. A recent study underlined how much difference there is between the doctor's perception of patients' physical and psychological discomforts and what is actually reported by the patients themselves. It was noted that the doctor's perception of the patient's discomforts as insufficiently serious could lead to the removal, in the mind of the patient, of any justification for communicating them to the doctor [42].

The introduction of an instrument which values patients' needs within a hospital ward and which allows for systematic collection of information has as its prime objective the improvement of the hospital staff's comprehension of the patient's physical and psychological state.

The NEQ questionnaire does not aim to estimate the patient's satisfaction, but to assess his needs in order to allow health professionals to activate a more focused intervention at different levels.

If the goal is to better focus an intervention, the need must be determined at the right time. In fact, the NEQ is submitted during the first days after admission (preferably the third) to the hospital; it is not submitted the first day because, in the case of patients admitted for the first time, it is necessary to allow them time to settle into the hospital and consider what they really need.

Therefore, the times of submission differentiate the NEQ from a satisfaction questionnaire that, by contrast, is necessarily submitted to the patient at the end of a period of care.

Most of the needs listed in the questionnaire regard the relationship between the patient and the care team and refer more to relational aspects (need of reassurance information and dialogue) than to the kind of treatment.

Awareness of these needs, as well as those related to the familial and social sphere, helps to broaden the accustomed perspective of the team, and directs greater attention to the needs expressed by the patient, providing, when possible, their solution.

The next step is to examine closely the meaning of the needs expressed by patients and make sure that they are met in an appropriate manner. For this, given the composite nature of needs revealed by hospitalised cancer patients, it will be necessary to initiate the planning of a *multidisciplinary* encounter which foresees the involvement, in addition to physicians and nurses, of other specialists such as psychologists, social workers, and volunteers.

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