Original Article

Towards a New Clinical Tool for Needs Assessment in the Palliative Care of Cancer Patients: The PNPC Instrument

Bart H.P. Osse, MD, Myrra J.F.J. Vernooij, PhD, Egbert Schadé, MD, PhD, and Richard P.T.M. Grol, PhD

Center of Quality of Care Research (B.H.P.O., M.J.F.J.V., R.P.T.M.G.), University of Nijmegen, Nijmegen; and Department of General Practice (E.S.), Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

Abstract

This study describes a new clinical tool for needs assessment in palliative care: the Problems and Needs in Palliative Care questionnaire (PNPC). It was developed to support the provision of care tailored to the specific demands of patients, which only can be provided when their needs are clearly identified. To test validity and reliability, 64 patients with metastatic cancer living at home completed the PNPC. Of 140 initial items, 2 were deleted because of low response. No important topics were missing. Dimensions were proposed to organize the problems and needs in a logical and practical array for use in individual patients, and to enable statistical analysis of patient-groups. Reliability analysis supported the proposed dimensions, with Cronbach's alpha coefficient >0.70 *for dimensions with* ≥ 5 *items, and alpha* >0.65 *for the 3- and 4-item dimensions. However, the dimensions* 'physical symptoms' *and* 'social issues' *lacked coherency with some low item-total correlations. The PNPC demonstrated convergent validity with the European Organization for Research and Treatment of Cancer (EORTC) and COOP-WONCA quality-of-life measures. These data are a first step in validating the PNPC, although the* 'social issues' *dimension needs reconsideration. Further studies are needed to evaluate clinical use.* J Pain Symptom Manage 2004;28:329–341. © *2004 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words

Needs assessment, palliative care, questionnaires, psychometrics, quality of healthcare, quality of life

Introduction

This article describes a new clinical instrument for needs assessment in palliative care, an increasingly important topic as the face of cancer has changed in the last few decades. Due to early detection and improved methods of treatment, more patients live a long period with a diagnosis of disseminated cancer.[1–3] These patients are confronted with a completely changed prospect: a life with permanent and progressive disease, and only a slim chance of cure. This knowledge has a tremendous psychological and social impact. Not only do

Address reprint requests to: Bart H.P. Osse, MD, WOK 229, P.O. Box 9101, 6500HB Nijmegen, The Netherlands.

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patients have to cope with a limited life expectancy, they also have to struggle with the fear of suffering, which may often be worse than their actual fate. Physical symptoms restrict physical and social activities. Usual activities may seem futile, and even finding something to fill the hours of the day may seem difficult.[4–6]

As the prospects of a cure slip away, care providers need to focus on the amelioration of the quality of life.[7] Although it is primarily the patients' perspective that will determine the care needed.[8,9] not all patients take the initiative to make their problems known. Time in consultations is limited and patients may be unaware of available services and treatment opportunities, or hesitate to report their problems and opinions because of a variety of psychological mechanisms. These include depression and denial, fear of treatment, fear of loss of autonomy, not wanting to bother a doctor with futile or non-medical problems, or a lingering grudge against the doctor after presumed medical faults.[5,6,10–13] Professionals, having lost their medical aim of a cure, often wait quite passively for patients to report their problems and needs for care and fail to address all issues important to patients.[14–16] Thus, important problems may not be addressed in a timely manner, causing unnecessary suffering and possibly leading to an escalation of the problems.[17–19] A systematic, active assessment of the problems and needs for care of cancer patients might help overcome these problems, and contribute to a better quality of care.[20]

Specific tools might support such an assessment.[21,22–25] Existing instruments were evaluated in a systematic literature review, but these proved to have important limitations.[26] Most instruments were developed for research purposes, and may not suit the purposes of clinical practice. None of the instruments covered all dimensions in palliative care, and in most instruments, the experience of a problem or dissatisfaction with care was not clearly distinguished from a need for more or better care. The conclusion of this review was that further development of practical tools for systematic needs assessment was required.

Consequently, a new patient-centered tool for needs assessment in palliative care has been constructed: the Problems and Needs in Palliative Care questionnaire (PNPC). It addresses experienced problems and the needs for care separately, because patients might not want professional care for every problem they experience.[27] Prior to wide clinical use, research is required to demonstrate that the PNPC is a valid and reliable instrument that complies with clinical requirements. This article reports a study of 64 palliative cancer patients living at home. The research question was: To what extent do the psychometric characteristics of the PNPC comply with the requirements of validity and reliability?

Methods

The PNPC Instrument

The PNPC was constructed as a comprehensive checklist of the problems patients experience in palliative care, and their needs for care (addressed as their desire for (more) professional attention). The PNPC used in this study was in Dutch. For this report, two researchers with help of a native English speaker translated the items, and a backward translation-check was performed by an independent third to ensure validity of this translation. The (translated) PNPC is described in the Appendix.

To construct the PNPC, a two-step qualitative study was carried out.[28] The first of these steps was fully explorative: in-depth interviews of nine cancer patients and their closest life companions (mostly their partners). In the second step, structured interviews were held with 31 patients after they had completed a draft version of the new instrument under construction. Interviews were also held with professionals working in the field: members of home-care organizations, pain teams, and specialist oncology nursing teams. In addition to this, the item content of existing needs assessment instruments was analyzed.[26] Two researchers, supported by a team of experts, combined the results of all these activities to construct the PNPC in the form used in this study. A structure was proposed with dimensions derived from the literature and the qualitative studies. To tailor the PNPC to each individual's situation, patients are invited to add any additional issues at the end of each dimension.

In this study, the psychometric characteristics of the PNPC instrument were evaluated. It is part of a program in which the PNPC is being developed and tested.

Sample and Procedure

The PNPC was tested in a sample of Dutch cancer patients who had a variety of cancer diagnoses, were in a palliative phase of treatment, and were living at home. General physicians, internists in outpatient clinics and cancer-patient organizations selected the patients. In a previous study, we had initially asked to include patients with 'incurable cancer,' which resulted in a sample of bedridden patients in a final terminal phase only. This was probably because physicians felt they would have deprived patients still in good condition of hope if they had formalized their palliative status. To avoid such bias in this study, the palliative phase was operationalized as: *cancer patients with distant metastasis.*

The formal inclusion criteria were:

Adult, non-institutionalized patients, residing in their own homes;
Cancer with distant metastasis, regardless of specific cancer type;
Patients able to complete questionnaires in the Dutch language;
Patients willing to discuss the PNPC in consultation with their physician.

Exclusion criteria were:

A physical or mental condition impeding the use of a questionnaire;
A life expectancy that was too short to allow the PNPC to be completed and properly discussed, as judged by the physician (minimal estimated life expectancy was about a week).

The Medical Ethics Committee of the University of Nijmegen approved the study. Patients were recruited and, after giving informed consent, asked to complete the PNPC at home at their own pace, together with additional questionnaires for research purposes. In the next consultation with their physician, they used the PNPC to discuss their problems and needs for care. The closest family member was asked to complete a tool rather similar to the PNPC, but focused on caregiver aspects (not reported here). Most patients and family completed their questionnaires simultaneously. They were instructed to discuss their problems among themselves only after filling in their questionnaires.

Validity

The validity and reliability of the PNPC were evaluated in several ways:

The *appropriateness* of items was evaluated through the item-response frequencies. An item was judged suitable for a checklist of systematic needs assessment if at least 10% of the patients recognized it as relevant for their situation.

Comprehensiveness was evaluated by studying all the additions and comments written by the patients on the questionnaire. Each comment was evaluated separately by two researchers and then discussed to consider whether any important topics were missing.

The *internal consistency* of the PNPC dimensions was measured by Cronbach's α coefficient. A reliability score (α) >0.70 is considered satisfactory for group comparisons.[29–32]

A further support for validity of the PNPC was sought in its *correlations with well-established measures.* A true criterion-validity test was not possible because there is no gold standard for needs assessments. Nevertheless, a presumed relationship between *problems* and *health-related quality of life* (further abbreviated to HRQL)[33,34] provided an opportunity to examine validity. This relationship was tested with two well-established HRQL measures; the European Organization for Research and Treatment of Cancer (EORTC)-QLQ-C30 questionnaire[35–37] and the COOP-WONCA charts.[38–40] A higher prevalence of *problems* in a PNPC dimension should be reflected in lower quality-of-life scores. We expected a substantial correlation of the *problem aspect* of PNPC domains with the quality-of-life dimension with an analogous content:

PNPC activities of daily living (ADL) and instrumental activities of daily living (IADL) with EORTC *physical functioning* and COOP *daily activities;*
PNPC *physical symptoms* with EORTC *fatigue, nausea/vomiting, pain, dyspnea, insomnia, appetite,* and COOP *physical complaints;*
PNPC *role activities* with EORTC *role functioning* and COOP *social activities;*
PNPC *financial and administrative issues* with EORTC *financial difficulties;*
PNPC *social issues* with EORTC *social functioning* and COOP *social support;*
PNPC *psychological issues* with EORTC *emotional functioning* and COOP *feelings.*

Correlations of the 'need for care' aspect of these 6 PNPC domains with the corresponding quality-of-life domains were also calculated. We

assumed that the needs for care are influenced by the quality of care already received, the availability of informal care (support and help from family and friends), and the common tendency of patients to ask for help. Therefore we expected that these correlations would be less strong. Dimensions in the PNPC that have no corresponding dimensions in EORTC or COOP-WONCA were excluded from this validity test.

Analysis

The completed questionnaires were rendered anonymous and further analyzed statistically with the SPSS 9.0.1 program. In order to assess the correlations of PNPC-domains with quality-of-life measures, a mean item score of each of the proposed PNPC dimensions was computed. Since the EORTC-scores, the COOP-scores and most of the PNPC-dimension-mean scores were not normally distributed (Kolmogorov-Smirnov test), the non-parametrical Spearman's rho was used to calculate correlations between the PNPC dimension-mean scores and domain-scores of the EORTC and item scores of the COOP-WONCA charts.[35,38,41]

Results

Sample

The patient population had a wide variation in age, social background, and cancer type (Table 1). Women with breast cancer were overrepresented in our sample in relation to incidence and (scarce) prevalence data.[1,2,42] Most patients knew they had cancer for more than 3 years. The quality-of-life status of the patients showed a wide variation, but was generally not too bad. There were no indications of specific patient groups refusing to participate. We asked referral sources to report cases where patients had declined to co-operate: only one was reported. However, of the 81 patients who initially volunteered, 16 did not complete this study, leaving $n = 64$ in our analysis. Reasons for dropping out were: death (4 patients), moving away (2 patients), and perception of the PNPC as too wearisome (2 patients). The reasons for dropping out of others are unknown. Forty-three general practitioners (GP) and 5 internists were involved in this study.

Appropriateness of Items (Table 2)

Only two items, *'stoma problems'* and *'wounds or decubitus'*, both from the dimension 'Physical symptoms' had an extremely low response. Each of these problems was experienced by only one patient (<2% of study population). Nobody asked for more attention for either one. Consequently, these two items were deleted from the PNPC and excluded from further analysis. Response on all other items concerning quality-of-life-related problems was 12% or more; some items represented problems relevant for almost 90% of the respondents. All items concerning informational needs showed high response. For most of the items in the dimensions 'concerning the GP' and 'concerning the specialist,' ≥10% of patients expressed a need for more professional attention. Items scoring <10% were *'That the GP discusses things that have gone wrong'* (7% wanted more attention) and *'That the GP supports me if I want something different from what he/she proposes'* (9%), *'That the specialist lets me shuttle less often to the hospital'* (7%), and *'That the specialist takes care of enough privacy during a consultation or medical investigation'* (5%).

Comprehensiveness

Patients wrote additional comments in 43 of the 64 questionnaires. In total, 154 comments were made, generally 1 or 2 additions per patient (range 0–17). Many of the comments were just a fine-tuning or further specification of existing PNPC items. Most other comments were expressions of satisfaction with their caregivers. We considered the very few new items brought up either not fitting, or too specific, to include in the PNPC.

Dimension Structure

The standardized Cronbach's α and item-scale correlations (corrected for overlap) are shown in Table 3.

Reliability of the Dimensions

Reliability as a measure of internal consistency showed Cronbach's $\alpha < 0\ .70$ for two dimensions: 'Role activities (4 items)' ($\alpha = 0.68$) and 'Problems in consultations (3 items)' ($\alpha = 0.67$). The other dimensions showed adequate scale reliability. The 'need for care' scales showed high internal consistency. Item-total

Table 1
Patient Characteristics

Personal Characteristics	*n*	%	Disease Characteristics	*n*	%
Age			Primary Tumors		
Range (years)	30–87		Breast[a]	29	45.3
Mean (years)	57		Lung	3	4.7
SD (years)	13.0		Esophagus/stomach	1	1.6
Median (years)	55		Colon/rectum	11	17.2
			Ovary	5	7.8
Gender			Malignant melanoma	4	6.3
Male	12	18.8	Cervix[a]	3	4.7
Female	52	81.3	Prostate	2	3.1
			Neck/head	1	1.6
Social Situation			Hematological/lymph system	1	1.6
Single	4	6.3	Primary liver cancer	1	1.6
Married	45	70.3	Pancreas	1	1.6
Living with life companion	3	4.7			
Widowed	8	12.5	Unknown primary origin	4	6.3
Living apart from life companion	3	4.7			
Living with others	1	1.6			
Total	64			66[a]	103.1[a]
Medical treatment until now			Time since diagnosis		
Operation	49	75.6	Range (months)	1.5–276	
Radiotherapy	35	54.7	Mean (months)	47.6	
Chemotherapy	36	56.3	SD (months)	48.9	
Stoma (urinary and/or rectal)	6	9.4	Median (months)	39.0	
Performance status	mean	SD		mean	SD
(EORTC QLQ-C30)					
Physical functioning[b]	57.2	25.4	Fatigue[c]	46.6	27.5
Role functioning[b]	48.9	36.0	Nausea and vomiting[c]	20.4	28.8
Emotional functioning[b]	72.4	22.9	Pain[c]	32.5	32.0
Cognitive functioning[b]	79.3	22.9	Dyspnea[c]	22.8	30.4
Social functioning[b]	72.8	26.8	Insomnia[c]	24.7	31.5
Global health/QOL[b]	67.1	18.9	Appetite loss[c]	8.2	30.7
			Constipation[c]	11.3	17.9
			Diarrhea[c]	12.5	24.8
			Financial difficulties[c]	12.6	21.2

[a]Two patients had breast and cervix cancer.
[b]Function scores (0–100); higher scores indicate better functioning.
[c]Symptom scales (1–100); higher scores indicate higher symptom distress. (According to EORTC QLQ-C30 scoring manual ISBN 2-930064-05-6).

correlations were above 0.20 except for 'Physical symptoms (18 items).'

Validity in Terms of the Relationship with the Quality-of-Life Measures

Table 4 shows the correlations of the PNPC dimensions summed-scores with some dimensions of two HRQL measures; the EORTC-QLQ-C30 and COOP-WONCA charts.

Almost all 'problem' dimensions in the PNPC showed a significant correlation with related HRQL dimensions. The highest Spearman's rho values were found for the PNPC dimension 'ADL and IADL.' The 'physical symptoms' dimension of the PNPC correlated with all the EORTC physical symptom scales and with the COOP item *'physical complaints'*. The PNPC dimensions, 'Psychological issues', 'Role activities' and 'Financial and administrative issues' correlated >0.40 with the corresponding HRQL domains. Only the PNPC 'Social issues' dimension correlated <0.40 with the EORTC domain, and with COOP *'social support.'* The PNPC dimensions showed an almost consistent higher correlation of their 'problem' aspect with the HRQL dimensions than with their 'need for care' aspect. Only the EORTC *dyspnea* and *financial difficulties* scales correlated marginally higher with the 'need' aspect of the PNPC dimensions.

Discussion

This study has addressed the issue of the validity and reliability of a new instrument for needs assessment in palliative care: the PNPC. We

Table 2
Item Response in PNPC Dimensions (n = 64)

Dimension (No. Items)	Problems[a]	Unmet Needs for Care[b]
ADL & IADL (7)	25–87%	0–16%
Physical symptoms (18)[c]	16–89%	0–16%
Role activities (4)	25–50%	4–13%
Financial/administrative issues (5)	16–48%	5–25%
Social issues (15)	18–51%	3–12%
Psychological issues (15)	17–89%	2–25%
Spiritual issues (5)	39–67%	5–22%
Autonomy (9)	44–79%	7–22%
Problems in consultations (3)	39–63%	18–27%
Overriding problems in the quality of care (9)	12–40%	0–24%
Concerning the GP (20)	—	7–33%
Concerning the specialist (19)	—	5–36%
Informational needs (9)	—	33–54%

This table shows the range of the item response within each dimension. The *problem* aspect and *unmet need for care* aspect are shown in separate columns.
[a]'Is this a problem?': cumulative answers: *Yes* + *Somewhat*
[b]'Do you want attention for this?': answer: *Yes, more*
[c]From the original 20 items from the dimension *physical symptoms,* 2 items were deleted because of low response.

found that, as far as item response frequencies can tell, almost all of the many problems addressed in the PNPC were experienced as relevant by cancer patients. The PNPC was also comprehensive, seeing that written comments did not elicit any further important topics.

We have attempted to group PNPC items into dimensions related to the World Health Organization quality-of-life concept. For use in individual patients, these dimensions are useful assets to organize the problems and needs in a logical and practical pattern. This helps to structure needs assessment and communication of needs. However, to use aggregated dimension scores in individual patients, a solid knowledge is necessary of the clinical relevance of these dimension scores and a much higher precision is required (Cronbach's $\alpha > 0.90$).[29] Consequently, PNPC dimension scores should not be used in individuals. Nevertheless, dimensions can be used in the analysis of problems and needs in groups of patients, and validation of the dimensions increases the value of an instrument such as the PNPC. In palliative care, collection of data is difficult, and any effort to obtain data that can serve more than one goal should be appreciated. Information gathered with the PNPC may be valuable for involved professionals to register the problems they encounter, to evaluate their performance, and to identify areas of structural deficit in care. Dimensions scores also can be useful in scientific research. For most dimensions, the reliability was satisfactory; only two had α' s slightly below 0.70. This is not extremely bad considering that these two were the shortest, with only 3 and 4 items, and that the reliability of a scale increases with the number of items. However, the 'Physical symptoms' dimension cannot be considered to be coherent, with item-total correlation below 0.20. Also the 'Social issues' dimension had items with only marginally sufficient item-total correlation. Most PNPC dimensions revealed the expected convergent validity with the EORTC and COOP-WONCA quality-of-life dimensions, and the hypothesized pattern of the 'need for care'-aspect showing lower correlations than the 'problem'-aspect of PNPC dimensions with HRQL dimensions was confirmed.

Table 3
Results of Reliability Analysis for Proposed PNPC Dimensions

	Problem Aspect		Need for Care Aspect	
PNPC Dimension (No. Items)	A	B	A	B
ADL & IADL (7)	0.89	0.62–0.81	0.89	0.50–0.84
Physical symptoms (18)	0.74	0.10–0.53	0.85	0.18–0.64
Role activities (4)	0.68	0.36–0.56	0.73	0.45–0.65
Financial/administrative issues (5)	0.76	0.36–0.62	0.80	0.45–0.68
Social issues (15)	0.79	0.22–0.67	0.89	0.33–0.75
Psychological issues (15)	0.84	0.29–0.65	0.92	0.51–0.77
Spiritual issues (5)	0.74	0.37–0.64	0.86	0.64–0.77
Autonomy (9)	0.86	0.41–0.68	0.88	0.43–0.76
Problems in consultations (3)	0.67	0.31–0.58	0.81	0.57–0.75
Overriding problems in the quality of care (9)	0.77	0.29–0.63	0.86	0.39–0.73
Concerning the GP (20)	—	—	0.91	0.29–0.79
Concerning the specialist (19)	—	—	0.92	0.29–0.75
Informational needs (9)	—	—	0.82	0.25–0.70

A = standardized Cronbach's α
B = range of item-total correlation

Table 4
Correlation of PNPC Dimensions with HRQL Dimensions

PNPC dimension (No. Items)	HRQL Dimensions Expected to Correlate	Problem Aspect of PNPC	Need for Care Aspect of PNPC
ADL & IADL (7)	EORTC physical functioning	−0.74	−0.60
	COOP daily activities	0.75	0.60
Physical symptoms (18)	EORTC fatigue	0.62	0.55
	EORTC nausea and vomiting	0.47	0.31[a]
	EORTC pain	0.51	0.51
	EORTC dyspea	0.46	0.53
	EORTC insomnia	0.53	0.51
	EORTC appetite	0.52	0.37
	COOP physical complaints	0.55	0.42
Role activities (4)	EORTC role functioning	−0.44	−0.36
	COOP social activities	0.54	0.43
Financial/ administrative issues (5)	EORTC financial difficulties	0.66	0.69
Social issues (15)	EORTC social functioning	−0.32[a]	n.s.
	COOP social support	0.37	0.31[a]
Psychological issues (15)	EORTC emotional functioning	−0.69	−0.56
	COOP feelings	0.61	0.61

Spearman's correlations of sum-scores of proposed PNPC dimensions with the scores of corresponding HRQL dimensions in the EORTC-QLQ-C30 and COOP-WONCA charts.
Values are significant at 0.01
[a] = significant at 0.05
n.s. = not significant

Deleting items based on the prevalence of problems (<10%) needs some justification. Some problems occur only very rarely, and may seem irrelevant. But the fact that some events may be rare does not imply that they are insignificant. A problem may be uncommon in a population, but might nevertheless seriously threaten an individual patient's well-being, and communicating such a problem to professionals may be of vital importance. We feel that the two items we deleted could be safely discarded, because the few patients who did experience these problems expressed no need for extra care. Moreover, patients always have the opportunity to add issues they feel are missing to the PNPC. However, when the PNPC is used in specific populations (e.g., colorectal cancer patients or head and neck cancer patients), the items might need some reconsideration and the development of disease-specific modules could be considered.

The results of our study give a reassuring picture of the validity and comprehensiveness of the PNPC. Despite this, the PNPC has its limitations. First, and most obvious, handing over a completed checklist does not make further communication redundant. A further exploration of the problems might be necessary (in 'pain,' for example, the localization, character, duration and intensity). Also, when patients indicate a need for care, a further dialogue (and sometimes other professional expertise) is necessary to determine the most appropriate intervention. Further, we must emphasize that not all problems weigh equally important in the quality of life of the patient.[43] For instance, uncontrollable pain or a serious crisis in the relationship with the life companion can overshadow all other problems. Finally, the PNPC may not be appropriate for every patient, since some ability to contemplate is required, as is the will to perceive one's own situation clearly.

The PNPC differs from quality-of-life instruments in three aspects. First, the PNPC specifically addresses needs for care. Second, the PNPC addresses issues concerning the quality of (health)care, and third, the PNPC is built as a comprehensive checklist instead of a short measure of a theoretical concept. Advantages of information gathered with the PNPC compared to quality-of-life measures should be that, aside from a more detailed picture of experienced problems, it clarifies what patients want to change in their professional care. It empowers patients by giving them the opportunity to direct professional care to the issues for which they want more professional attention.

One can speculate about the clinical value of the PNPC, and many questions still remain. Will it help professionals and patients initiate discussion on topics they might otherwise be reluctant

to raise[44]? Even more basically, does the opportunity to hand over a questionnaire help GPs to overcome hesitation to initiate a (renewed) contact with patients when a cure of the cancer becomes out of reach? Will patients find the PNPC helpful to survey their personal situation and to structure their thoughts? Will it help to initiate discussions with relatives? Does repeated use during a period of care provide palliative care providers with valuable data to evaluate their performance, and can this be done without burdening the patient too much? These speculations indicate that further research is needed.

Limitations

One limitation of this study is that our sample, predominantly women with breast cancer, may not have been completely representative of the total population of homebound palliative cancer patients.[3] The use of GPs, internists and patient-organizations in recruiting respondents might have caused selective sampling. However, the recruited population seems appropriate for the purpose of the validation of the PNPC questionnaire, because when physicians use the PNPC in their 'normal' palliative care, and when patient organizations encourage the use of the PNPC, we expect they also will select patients and reach a population similar to our study population. Another limitation lies in the sample size, which limited the possibilities for analysis. When larger samples are available, further evaluation of the domains through factor analysis is necessary. Further validation is also necessary with regard to the responsiveness of the PNPC to changing situations and with regard to changes in time. The PNPC used in this study was in Dutch, and although we translated the items for this presentation carefully, a further validation of the cross-language/cross-cultural translation is necessary before use in English-speaking populations is pursued.

Future Developments of the PNPC

There is tension between the requirements for the PNPC. The desire for completeness tends to lengthen the questionnaire, while feasibility calls for brevity. In the extended form used in this study, the PNPC seems to be complete, but maybe not as feasible as we would have liked. Future developments should aim to improve feasibility while maintaining validity.

Conclusion

There is empirical evidence supporting the validity and reliability of the PNPC, but this is only one step in the development of a new instrument and many may still be needed. Further research is necessary to ascertain the effects of the use of the PNPC as a clinical instrument on patient satisfaction with care, their quality of life, and the use of care provisions.

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Appendix

The Problems and Needs in Palliative Care Questionnaire: Dimensions and Items (Translated from the Dutch original)

The PNPC asks 2 questions at each item:

1. Is this (item) a problem? *Yes— Somewhat— No*
2. Do you want (professional) attention for this (item)? *Yes, more – As much as now – No*

Quality-of-Life Aspects

Activities of Daily Living and Instrumental Activities of Daily Living: 7 Items

1. Difficulties in body care, washing, dressing, or use of the toilet.
2. Difficulties in rising, walking, climbing stairs.
3. Difficulties in preparing meals or cooking.
4. Difficulties in shopping (food, clothes etc.).
5. Difficulties in personal transportation (cycling, driving a car, using public transportation etc.).
6. Difficulties in doing light housework (tidying up, etc.).
7. Difficulties in doing heavy housework (cleaning, making beds, gardening etc.).

Physical Symptoms: 18 items

1. Pain
2. Difficulty in concentration
3. Fatigue
4. Sleeping problems
5. Nausea or vomiting
6. Constipation or diarrhea
7. Incontinence
8. Mouth problems or swallowing problems
9. Lack of appetite or change of taste
10. Shortness of breath
11. Cough
12. Itch
13. Loss of hair
14. Impaired vision or hearing
15. Sexual dysfunction
16. Prickling or numb sensation
17. Swelling of arms, legs or abdomen (Edema)
18. (Nightly) sweating or hot flushes

(deleted: Wounds or pressure sores)
(deleted: Problems with a stoma)

(*Continued*)

Appendix
Continued

Role Activities: 4 Items

1. Difficulty in filling the day.
2. Difficulty in relaxing.
3. Difficulties in employment or following a study.
4. Difficulties in caring for children or babysitting.

Financial and Administrative Issues: 5 Items

1. Extra expenditure because of the disease.
2. Reduced income because of the disease.
3. Difficulties in making arrangements (last will and testament, insurance etc.).
4. Difficulties in filling in forms.
5. Difficulties in making my life companion acquainted with financial and administrative issues.

Social Issues: 15 Items

1. Problems in the relationship with life companion.
2. Difficulties in talking about the disease with life companion.
3. Problems in the contact with (one of) the children.
4. Problems in the contact with family, friends, neighbors or colleagues.
5. Finding it difficult to talk about the disease, because of not wanting to burden others.
6. Finding others not receptive to talking about the disease.
7. Difference of opinion what treatments should be used.
8. Experiencing too little support by others.
9. Difficulties in finding someone to talk to (confidant).
10. Receiving too little practical help from life companion, or from the family.
11. Others being over-concerned.
12. Others dramatizing the situation.
13. Others denying the severity of the situation.
14. Loneliness.
15. Being forsaken by others.

Psychological Issues: 15 Items

1. Depressed mood.
2. Not experiencing pleasure anymore.
3. Fear for physical suffering.
4. Fear of treatments.
5. Fear of metastases.
6. Fear of being alone.
7. Fear of death
8. Difficulty coping with the unpredictability of the future.
9. Difficulties in showing emotions.
10. Feelings of guilt.
11. Feelings of shame.
12. Loss of control over emotions.
13. Difficulties to accept a changed bodily appearance.
14. Difficulties to See positive aspects of the situation.
15. Being overwhelmed by all decisions that have to be made.

Spiritual Issues: 5 Items

1. Difficulties to be engaged usefully.
2. Finding it hard to be available to others.
3. Difficulties in keeping confidence in God or religion.
4. Difficulties concerning the meaning of death
5. Difficulties in accepting the disease.

Autonomy: 9 Items

1. Difficulties in continuing the usual activities.
2. Difficulties in continuing social activities.
3. Difficulty in handing over tasks of another person because one is no longer able to perform former tasks.
4. Being dependent on others
5. Frustrations because one can do less than before.
6. Experiencing loss of control over one's own body.
7. Experiencing loss of control over one's life.
8. Experiencing difficulties in asking for help.
9. Experiencing difficulties in making one's own decisions.

(*Continued*)

Appendix
Continued

Informational Needs: 9 Items (only addressed yes/no)

1. Information about aid (such as wigs, prosthesis, alarm devices, parking permits for the disabled, special beds, adaptations to the home, etc.).
2. Information about places and agencies that provide help (and aids).
3. Information about the cause of cancer.
4. Information about possibilities of treatment and the side effects.
5. Information about physical symptoms that can be expected.
6. Information about alternative healing methods.
7. Information about euthanasia.
8. Information about nourishment.
9. Information about the sexuality of people with cancer.

Quality-of-Care Aspects:

Problems in Consultations: 3 Items

1. Experiencing difficulties in expressing disagreement.
2. Experiencing difficulties in saying one doesn't understand.
3. Experiencing difficulties in remembering what was said.

Overriding Problems in Quality of Care: 9 Items

1. The possibility to choose another care provider.
2. Insufficient adjustment of hospital care to the home situation.
3. Difficulties fine-tuning the care of different professionals.
4. Difficulties in getting access to help from agencies/professional organizations.
5. Too slow professional reaction on an acute change in situation.
6. The insecurity of the availability of a hospital bed if needed (acutely).
7. Too many caregivers around me in my house.
8. Difficulties in getting a second opinion from another doctor.
9. Lack of information in writing (inability to reread information).

Concerning the GP: 20 Items

Do you want his/her attention for this? Yes, more – As much as now – No

1. That the GP has knowledge of treatment possibilities.
2. That the GP discusses things that went wrong in the past.
3. That the GP announces a house visit in advance.
4. That the GP comes to check if I am alright.
5. That the GP visits me in the hospital.
6. That the GP takes the time to discuss some issues.
7. That the GP takes the initiative to visit me.
8. That the GP shows his interest in me as a person.
9. That the GP listens well to what I have to say.
10. That the GP supports me if I want something different from what he proposes.
11. That the GP helps me when I have to make difficult decisions.
12. That the GP discusses what I want, and what I can expect from him in the future.
13. That the GP provides intelligible information on own initiative.
14. That the GP is honest and open about my situation.
15. That the GP supports me when I am having hard times.
16. That the GP involves my family in the care.
17. That the GP has more attention for the personal needs of my family.
18. That the GP arranges that I can speak to him personally if something happens.
19. That the GP confers with the medical specialists.
20. That the GP informs other care providers (e.g., by using a common medical file).

Concerning the Specialist: 19 Items

Do you want his/her attention for this? Yes, more– As much as now – No

1. That the specialist discusses things that went wrong in the past.
2. That the specialist takes care that I don't have to undergo unnecessary procedures.
3. That the specialist lets me shuttle to the hospital less often.
4. That the specialist looks after me when the treatment threatens to become too much for me.
5. That the specialist ensures enough privacy during a consultation or medical investigation.
6. That the specialist arranges the appointments so that I don't have to wait so long.
7. That the specialist takes ample time to discuss a few matters.
8. That the specialist shows me his/her interest in me as a person.

(*Continued*)

Appendix
Continued

9. That the specialist also supports me if I want something different from what he proposes.
10. That the specialist helps me to make difficult decisions.
11. That the specialist discusses with me what I want, and what I can expect from him/her in the future.
12. That the specialist tells me honestly and openly how my situation is.
13. That the specialist explains honestly things in simple words.
14. That the specialist supports me when I am having hard times.
15. That the specialist involves my family in the care.
16. That the specialist has more attention for the personal needs of my family.
17. That I don't have to speak with another specialist at control consultations.
18. That the specialist keeps my GP informed.
19. That the specialist arranges a good follow-up after I get bad news.