

Development and psychometric evaluation of patient needs assessment in palliative care (PNAP) instrument

RADKA BUZGOVA, PHD, RADKA KOZAKOVA, PHD, LUCIE SIKOROVA, PHD,
RENATA ZELENIKOVA, RN, PHD, AND DARJA JAROSOVA, PHD
Department of Nursing and Midwifery, Faculty of Medicine, University of Ostrava, Czech Republic
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ABSTRACT

Objective: Although assessment of palliative patients' needs is a key issue in palliative care, a suitable instrument for identification of such needs is not available in Central European countries. Our objectives were to produce an adequate tool for identifying the importance and satisfaction of palliative patients' needs and to verify its psychometric properties.

Method: The patient needs assessment in palliative care (PNAP) instrument was constructed based on a literature review and qualitative research (focus groups, $n = 5$). The psychometric properties of the questionnaire were verified by a cross-sectional study. The convergent validity of the questionnaire was determined by confirmatory factor analysis. Furthermore, internal consistency, test–retest reliability, and construct validity were also tested. The qualitative research group comprised 30 participants (27 experts in palliative care, 1 patient, and 2 family members). Psychometric properties were evaluated in a group of 349 hospital inpatients terminally ill with chronic disease or cancer and receiving palliative care.

Results: Based on the qualitative data analysis, a questionnaire was constructed that contained 42 items grouped into 5 domains. When testing the psychometric properties of the questionnaire, a new model containing 40 items in 7 domains was produced. Cronbach's α for the entire PNAP questionnaire was 0.89 on the importance scale and 0.80 on the satisfaction scale. Test–retest reliability was higher than 0.7 for all domains in both scales.

Significance of Results: The results of tests on the psychometric properties of the PNAP questionnaire showed at least satisfactory validity and reliability, and it can be employed to assess the needs of palliative care patients in Central European countries.

KEYWORDS: Palliative care, Needs assessment, Patients

INTRODUCTION

Assessment of palliative patients' needs is one of the key issues in palliative care (Sepúlveda et al., 2002), mainly because inadequately met needs significantly impair the quality of life for dying persons. Recognition of the individual needs of palliative care patients and their family members form a basis for providing individualized care. Needs assessment

allows identification of the areas that patients and their families consider important and where they need help and support (Waller et al., 2012). Implementation of care based on needs assessment requires a change in and especially a consensus on how to define individual needs and how and when to measure them (Carson et al., 2008).

Richardson et al. (2005) analyzed more than 30 tools for assessing the needs of patients in cancer care. The purposes of these assessment tools were to identify and prioritize patients' actual problems, to identify their preferences regarding treatment and care, and to monitor changes in their symptoms,

Address correspondence and reprint requests to: Radka Buzgova, Department of Nursing and Midwifery, Faculty of Medicine, University of Ostrava, Syllabova 19, Ostrava 700 30, Czech Republic. E-Mail: radka.buzgova@osu.cz

functioning, and well-being (Richardson et al., 2005). In their systematic review, Osse et al. (2000) evaluated nine questionnaires used to assess patients' needs in palliative care. Assessment tools may also be utilized for hospital inpatients with life-threatening diseases. They may serve as an instrument for evaluating treatment outcomes (Osse et al., 2007) and for developing communication between caregivers and patients (Weissman & Meier, 2011) and, possibly, their families as well (Tamburini et al., 2000; Wen & Gustafson, 2004). The potential benefit of assessment tools employed in both patients and their relatives has been reported in several studies (Sanson-Fisher et al., 2000; Deeken et al., 2003; Wen & Gustafson, 2004; Davidson et al., 2004; Grimshaw et al., 2005).

The need for improved care for patients with life-threatening or life-limiting conditions is unquestionable. A multidisciplinary team in hospice care is usually ready to solve patients' needs and problems. However, implementation of palliative care principles in the hospital setting is often problematic. Not all hospitals have multidisciplinary palliative care teams, and there are workforce shortages combined with tenuous funding (Weissman & Meier, 2011). Using assessment tools in patients eligible for palliative care while in hospital and subsequently dealing with important unmet needs identified by the patients may be one step toward individualized care.

The vast majority of published needs assessment tools come from the United States (Ganz et al., 1992; Gates et al., 1995; Coyle et al., 1996; Emanuel et al., 2001; Fortner et al., 2003), Great Britain (Cull et al., 1995; Thomas et al., 2001; Lidstone et al., 2003; Ewing & Grande, 2012), Canada (Crooks et al., 2004), and Italy (Tamburini et al., 2000), The Netherlands (Osse et al., 2007) and Australia (Waller et al., 2008; 2010; Bonevski et al., 2000). These questionnaires are multidimensional and employ various approaches to compiling lists of needs. In the Czech Republic, there is no suitable instrument for identifying the needs of a palliative care patient or for assessing quality of care. There are only Czech versions of questionnaires for assessment of quality of life in cancer patients, such as the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire–Core 30 (EORTC QLQ–C30).

Given the fact that the importance of (particularly psychosocial and spiritual) needs and their assessment may be influenced by the sociocultural context, it may not be sufficient to translate an already-existing standardized instrument produced within a different cultural setting. We therefore took the decision to develop our own questionnaire, one that may also be suitable for other Central European countries where there is no such tool.

Our objectives were to produce an adequate tool for identification of the needs of patients receiving palliative care and to verify its psychometric properties.

METHODS

Designing a Questionnaire

The questionnaire items were compiled based on a literature review (Liang et al., 1990; Diwan & Moriarty, 1995; Tamburini et al., 2000; Kellehear, 2000; Sothill et al., 2001; Edmonds et al., 2001; McIlmurray et al., 2003; Davies & Higginson, 2005; Richardson et al., 2005; Fitzsimons et al., 2007; Currow et al., 2008; Wijk & Grimby, 2008), an analysis of foreign tools (Richardson et al., 2005; Osse et al., 2007), and qualitative research (focus groups). According to Richardson et al. (2005), the selection of individual items related to needs is dependent on a professional's experience, that is, which information they perceive as important for clinical evaluation.

As a part of qualitative research, 5 focus groups were held, comprising a total of 30 participants, including 16 general nurses (hospice, home care, nursing home, long-term care facility, oncology department, and internal medicine department), 3 physicians (long-term care facility and hospice), 4 social workers, 2 clergypersons, 1 cancer patient, and 2 family members caring for terminally ill patients. On average, each focus group lasted for two hours. The sessions were held in two phases and conducted by a single moderator. During the first phase, the problems and needs of the palliative care patients were discussed. This basic question was addressed: "Based on your experiences, what are the biological, psychological, social, and spiritual needs of patients with respect to the quality of their lives?" All focus-group interviews were recorded and transcribed. Subsequently, quantitative data analysis was employed to define both domains related to the needs of palliative care patients.

In the second focus-group phase, foreign tools for needs assessment were discussed and individual items suitable for use in Czech patients analyzed. Questions were formulated by proposing domains and searching for suitable wording understandable to respondents. After all focus groups were completed, participants were once again asked whether individual items were appropriate for inclusion in the questionnaire and whether the wording was suitable for palliative care patients (as per the opinions of experts).

When developing the assessment tool, emphasis was placed on content validity, namely, the measurement aim, the target population, the concept to be

measured, item selection and item reduction, and interpretability of items (Terwee et al., 2007).

Evaluation of the Psychometric Properties of the Questionnaire

Subjects

Psychometric properties were evaluated in a group of 349 patients terminally ill with a chronic disease or cancer resident in University Hospital Ostrava and receiving palliative care. The criteria for inclusion in the study group were as follows: age over 18 years, and cancer or other terminal disease (e.g., end-stage chronic heart failure, chronic obstructive pulmonary disease, cirrhosis of the liver, kidney disease, such neurological disorders as dementia and multiple sclerosis, and polymorbid “frail” geriatric patients).

All patients were informed about the study objective and gave informed consent. The research was approved by the ethics committees of the University Hospital Ostrava and the Faculty of Medicine.

Validity and Reliability Criteria

The relevance of items was evaluated through item–response frequencies. After pilot testing of the questionnaire, its final version only contained those items that were related to needs identified as important by at least 10% of patients.

Convergent Validity

The convergent validity of the questionnaire was determined by confirmatory factor analysis. The robust maximum likelihood estimation was found correcting for nonnormal distribution of items. For individual models, the chi-squared value (χ^2), number of degrees of freedom (df), and their ratio were stated, together with the root-mean-square error of approximation (RMSEA), the comparative fit index (CFI), the Tucker–Lewis index (TLI), and the standardized root-mean-square residual (SRMR).

To confirm a good fit between the model and the data, the χ^2 value should be ≥ 0.05 (Barrett, 2007). Hooper et al. (2008) reported limitations in the use of the χ^2 test, particularly its sensitivity to sample size and normality of distribution. Therefore, researchers tried to find alternative markers for testing goodness of fit. An option is to determine the ratio of χ^2 to its degrees of freedom (Wheaton et al., 1977). The recommended cutoff value for the χ^2/df ratio is 2.0, with the upper limit being 5.0. For RMSEA, the recommended cutoff is a value close to 0.06 (Hu & Bentler, 1999), with a stringent upper limit of 0.07 (Steiger, 2007). The RMSEA confidence interval lower limit should be close to 0, and the upper limit should not exceed 0.08 (Hooper et al., 2008). The

CFI and TLI values should be close to 1.0 or at least exceed 0.90 (Hooper et al., 2008). The SRMR values should be less than 0.05, though values less than 0.08 are acceptable (Hu & Bentler, 1999).

Reliability

Internal consistency was determined using Cronbach’s α . Usually, the acceptable minimum is set at 0.70 (Terwee et al., 2007; Aaronson et al., 2002; Peterson, 1994). Streiner and Norman (2003) reported an acceptable minimum as low as $\alpha = 0.65–0.70$. This criterion was also utilized in our study.

Moreover, a corrected item–total correlation was performed, with an acceptable minimum of 0.40 (Ware & Gandek, 1998). Test–retest reliability was verified using Spearman’s correlation coefficient, with an acceptable minimum of 0.70 (Terwee et al., 2007). In repeated tests within 5 days, a total of 35 patients participated. Usually, 10% of subjects are used to assess test–retest reliability.

Construct Validity

Construct validity was verified using Spearman’s correlation coefficient between selected patient needs assessment in palliative care (PNAP) questionnaire domains and selected domains of the EORTC QLQ–C30 (Fayers et al., 2001), and the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). A nonparametric Spearman’s correlation coefficient was employed because of the nonnormal distribution of data (the Kolmogorov–Smirnov test). The levels of association were those applied by Feeny et al. (2005) as follows: high, $r > 0.50$; moderate, $r = 0.35–0.50$; weak, $r \leq 0.34$. Unmet needs for care are not only dependent on existing problems, but also on the desire to get help and the availability of care, and are thus expected to correlate less directly with quality of life (Osse et al., 2007). Therefore, at least a moderate correlation ($r > 0.35$) was expected between unmet needs and a lower quality of life in the related EORTC QLQ–C30 dimensions. Furthermore, an association between unmet needs in the emotional functioning domain and the HADS questionnaire was expected. All statistical tests were performed at a level of statistical significance of 5%. The data were analyzed using Stata (v. 10) software.

RESULTS

Constructing Questionnaire Domains, Facets, and Items: Content Validity

Construction of questionnaire domains, facets, and individual items was based on the first focus group

phase. The qualitative analysis identified 5 categories (domains of needs), 16 subcategories (facets of needs), and individual needs considered as important by the focus-group participants (46 items). The domains were as follows: physical functioning (facets: daily activities and symptoms; 14 items), psychological needs (facets: cognitive functioning, adaptation to disease, and reduction of anxiety and fear; 7 items), social needs (facets: social relations, support from caregivers, social inclusion, and security; 11 items), spiritual needs (facets: religious needs, meaning of life, and aesthetic needs; 10 items), and autonomy (facets: continuity of life, decision-making, dignity, and information; 4 items). The second phase of focus groups was aimed at searching for suitable wording of individual items and developing methods.

As an effective method for assessing the outcome of care, determination of the level of so-called unmet needs was selected. Unmet needs are defined as those identified by a patient as important and, at the same time, unsatisfied (Richardson et al., 2005). Two scales have been created: (1) Importance and (2) Satisfaction. The former is a 5-point scale on which the patient rates how important a particular item has been for him during the past week, ranging from 1 (not at all) to 5 (very important). The latter is a 5-point scale on which the respondent rates how an item (need) that is important for him or her is met, ranging from 1 (not at all) to 5 (yes, very much). Unmet needs are those identified by the respondent as both important (score 4–5) and unmet (score 1–2).

After completion of the focus groups, an expert analysis was carried out that selected 42 (of 66 proposed) items for pilot testing of the questionnaire. The process of questionnaire development is schematized in Figure 1.

Assessing Psychometric Properties of the Questionnaire

Subjects

The psychometric properties of the questionnaire were tested in a group of 349 patients with end-stage chronic disease or cancer patients who had discontinued curative treatment. The patients' mean age was 68.1 years ($SD = 12.8$). Their sociodemographic characteristics are shown in Table 1.

Item–Response Frequencies

After evaluation of individual items, the following two items with an importance less than 10% were eliminated (Figure 1): to have a chance to talk to someone about sexual needs and to solve problems with one's partner.

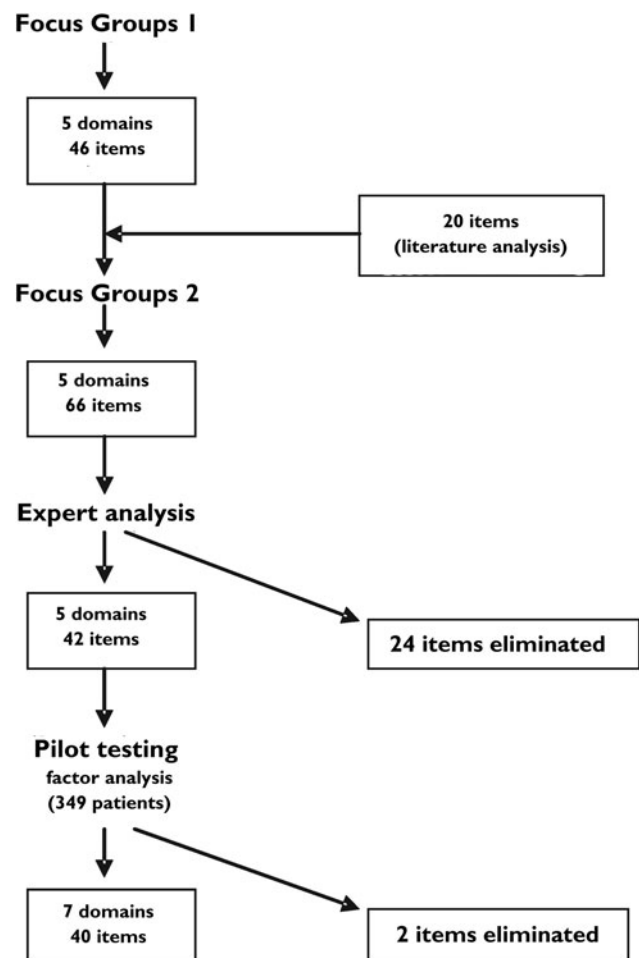


Fig. 1. Process of PNAP questionnaire development.

Confirmatory Factor Analysis

Confirmatory factor analysis was utilized to test the fit between the model and the data. In all models, the χ^2 was statistically significant, suggesting their refusal. However, the χ^2/df ratio was within the recommended range in all models, with model 4 being closest to the cutoff of 2.0.

The main aim of confirmatory factor analysis was to test the validity of the original model produced during questionnaire development. Model 1 contained five domains covering physical, psychological, social, and spiritual needs, as well as autonomy. The results in Table 2 clearly show that the fit between the model and the data was not good.

Therefore, a model 2 was produced that comprised seven factors (domains: physical symptoms, social area, respect and support from health professionals, meaning of life and reconciliation, autonomy, chance to share emotions, and religious needs). This second model showed a better fit with the data, but this fit was still not good enough. A problematic factor was domain 7 (religious needs), which only contained

Table 1. Sociodemographic characteristics of the group ($n = 349$)

Characteristics	<i>n</i> (%)	Characteristics	<i>n</i> (%)
Gender		Cancer diagnosis	225 (64.5)
Male	172 (49.3)	Mouth, pharynx, gastrointestinal tract	54 (24.1)
Female	177 (50.7)	Respiratory tract	37 (16.4)
Marital status		Bone	4 (1.8)
Single	15 (4.3)	Skin, soft tissues	13 (5.8)
Married	162 (46.3)	Breast, female reproductive organs	43 (19.1)
Divorced	56 (16.1)	Male reproductive organs	19 (8.4)
Widow/er	116 (33.3)	Urinary bladder	10 (4.4)
Children		Eye, central nervous system	11 (4.9)
Yes	311 (89.1)	Hematopoiesis	18 (8.0)
No	38 (10.9)	Others	16 (7.1)
Living		Chronic disease	124 (35.5)
In an institution	8 (2.3)	Chronic heart failure	43 (34.7)
Alone	104 (29.8)	Chronic obstructive pulmonary disease	11 (8.9)
With a partner	175 (50.2)	Liver cirrhosis	5 (4.0)
With children	50 (14.3)	Kidney disease	12 (9.7)
With other relatives	12 (3.4)	Neurological disease	5 (4.0)
		Multimorbidity in the elderly	48 (38.7)

two items and, moreover, did not correlate with the other factors. Therefore, this domain was not included in model 3. Another problematic issue was item 3 (ability to concentrate), which was transferred from the domain “physical symptoms” to the domain “autonomy” in model 4. This model, containing six factors and the transferred item 3, showed the best fit between model and data. The χ^2/df ratio of 2.116, RMSEA of 0.057, and SRMR of 0.074 demonstrated an acceptable fit between model and data. However, the CFI and TLI values did not meet the required criterion (>0.9) in any of the models.

The final version of the questionnaire was based on model 4 (item 3 transferred to the domain “autonomy”). However, domain 7 (“religious needs”) remained in the final version. It is our opinion that religious needs comprise an important domain for holistic needs assessment.

Reliability

Cronbach’s α for the entire PNAP questionnaire was 0.89 on the importance scale and 0.80 on the satisfaction scale. A Cronbach’s $\alpha > 0.65$ was found for all PNAP questionnaire domains in both the importance and satisfaction scales. Also, item–total correlation was higher than 0.4 for all items (Table 3), with the exception of two items in the domains “physical symptoms” and “autonomy” in the satisfaction scale. Test–retest reliability was higher than 0.7 for all domains in both scales.

When comparing Cronbach’s α for individual PNAP questionnaire domains in patients with chronic disease and cancer, no significant differences were found. Chronic patients were found to have a Cronbach’s α of 0.91 (domains: 0.69–0.89) in the importance scale and 0.83 (domains: 0.67–0.91) in the satisfaction scale. Cancer patients had a Cronbach’s

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

	Model 1	Model 2	Model 3	Model 4
χ^2	2299.712	1800.316	1662.875	1366.709
<i>P</i>	<0.001	<0.001	<0.001	<0.001
<i>df</i>	730	719	650	646
χ^2/df	3.150	2.504	2.558	2.116
CFI	0.608	0.730	0.713	0.796
TLI	0.581	0.707	0.690	0.778
RMSEA (<i>CI</i>)	0.079 (0.075–0.082)	0.066 (0.062–0.070)	0.067 (0.063–0.071)	0.057 (0.053–0.061)
SRMR	0.117	0.082	0.083	0.074

χ^2 (chi-squared test of model fit), *df* (degrees of freedom), CFI (comparative fit index), TLI (Tucker–Lewis index), RMSEA (root mean square error of approximation), SRMR (standardized root mean square residual), *CI* (confidence interval).

Table 3. Assessment of the PNAP questionnaire reliability

Domains	Importance				Satisfaction		
	Items	α for Domains (Items)	Item–Total Correlation	Test–Retest	α for Domains (Items)	Item–Total Correlation	Test–Retest
Physical symptoms	12	0.89 (0.87–0.98)	0.45–0.83	0.71	0.79 (0.78–0.82)	0.39–0.58	0.72
Social area	6	0.68 (0.65–0.71)	0.40–0.68	0.92	0.70 (0.68–0.82)	0.41–0.72	0.71
Respect and support from health professionals	5	0.65 (0.59–0.65)	0.58–0.70	0.77	0.86 (0.81–0.87)	0.57–0.75	0.79
Meaning of life and reconciliation	6	0.69 (0.65–0.73)	0.58–0.70	0.90	0.86 (0.82–0.87)	0.59–0.70	0.71
Autonomy	7	0.65 (0.61–0.66)	0.53–0.62	0.82	0.68 (0.65–0.71)	0.35–0.44	0.87
Chance to share emotions	2	0.73 (0.71–0.74)	0.88–0.90	0.78	0.84 (0.82–0.87)	0.73–0.74	0.81
Religious needs	2	0.91 (0.90–0.91)	0.95–0.96	0.93	0.77 (0.75–0.89)	0.65–0.66	0.89

α of 0.88 (domains: 0.69–0.92) in the importance scale and 0.79 (domains: 0.60–0.88) in the satisfaction scale. Questionnaire reliability, expressed as a Cronbach's $\alpha > 0.65$, was demonstrated for individual domains in both patient groups, the only exception being the domain "autonomy" in the satisfaction scale.

Construct Validity

In the satisfaction scale, a Spearman's correlation coefficient of $r > 0.35$ was found only for the domains "physical symptoms," "meaning of life," and "reconciliation and autonomy." For the domains "social area" and "chance to share emotions," a correlation was

also found, but a very weak one ($r = 0.12$ – 0.27). In the importance scale, a very low correlation ($r = 0.11$ – 0.24) was found and in only some domains (Table 4).

DISCUSSION

Although in most existing needs assessment tools psychometric properties have been published, not all meet the criteria of validity, reliability, responsiveness, and burden (Osse et al., 2000; Wen & Gustafson, 2004). Good reliability for the Needs Evaluation Questionnaire in assessing the needs of hospitalized cancer patient was reported by Tamburini et al. (2000).

Table 4. Correlation among the PNAP, EORTC QLQ–C30, and HADS

PNAP domains		Importance	Satisfaction
Physical symptoms	EORTC QLQ–30: physical function	0.11 (0.049)	0.38 (<0.001)
	EORTC QLQ–30: fatigue	n.s.	–0.36 (<0.001)
	EORTC QLQ–30: nausea and vomiting	n.s.	–0.23 (0.012)
	EORTC QLQ–30: pain	n.s.	–0.35 (<0.001)
	EORTC QLQ–30: dyspnea	0.24 (0.020)	–0.37 (<0.001)
	EORTC QLQ–30: insomnia	n.s.	–0.44 (<0.001)
Social area	EORTC QLQ–30: cognitive	0.17 (0.029)	0.33 (<0.001)
	EORTC QLQ–30: social functioning	0.18 (0.001)	0.22 (0.036)
	EORTC QLQ–30: financial difficulties	0.12 (0.023)	–0.23 (0.032)
Meaning of life and reconciliation	EORTC QLQ–30: emotional functioning	n.s.	0.51 (<0.001)
	HADS: depression	–0.16 (0.003)	–0.51 (<0.001)
	HADS: anxiety	n.s.	–0.54 (<0.001)
Chance to share emotions	EORTC QLQ–30: emotional functioning	0.24 (<0.001)	0.12 (0.038)
	EORTC QLQ–30: cognitive functioning	0.15 (0.004)	0.16 (0.032)
	HADS: depression	0.14 (0.011)	–0.21 (0.008)
	HADS: anxiety	0.20 (<0.001)	–0.27 (0.006)
Autonomy	EORTC QLQ–30: role functioning	n.s.	0.42 (<0.001)
	EORTC QLQ–30: physical functioning	n.s.	0.43 (<0.001)
	EORTC QLQ–30: social functioning	n.s.	0.41 (<0.001)

Spearman's correlation coefficient $r > 0.35$ printed in bold type.

The newly constructed PNAP questionnaire covers the area of the most frequent biopsychosocial and spiritual needs. It was created for palliative care patients dying of end-stage chronic disease or cancer with the aim of identifying unmet needs related to health and social care.

The originally proposed version of the questionnaire contained 42 items and 5 domains but did not show goodness of fit between model and data when confirmatory factor analysis was carried out. The final version of the questionnaire comprises 40 items grouped into 7 domains. Confirmatory factor analysis confirmed only part of the assumed structure.

The questionnaire was found to have borderline psychometric properties. The overall reliability of the questionnaire, determined by Cronbach's α , was good for both scales ($\alpha > 0.8$). In the importance scale, the coefficient was only borderline ($\alpha = 0.65\text{--}0.70$) for certain domains (social area, respect and support from health professionals, meaning of life, and reconciliation and autonomy). When assessing psychometric properties of the Problems and Needs in Palliative Care Questionnaire, Osse et al. (2007) reported a Cronbach's $\alpha < 0.65$ for two domains ("physical symptoms" and "social issues") in the importance scale.

In our study, the acceptable minimum was noted in test–retest reliability, and item–total correlation was observed for all domains.

The content validity of the questionnaire was ensured by an expert analysis performed by professionals who provide palliative care. Yet the domain "physical symptoms" may not include all problems related to a particular condition. Therefore, it would be advisable to produce special modules of the questionnaire covering the specific physical problems of a particular disease.

Social needs are covered by the questionnaire domains called "social area" and "respect and support from health professionals." Social needs are often created and also satisfied through social relations and communication. Social relations are a form of interpersonal interaction among individuals and groups (Tomágová, M. & Bóriková, 2008). For end-of-life patients, two social groups are important: their families and multidisciplinary teams of caregivers (McIllmurray et al., 2003). The primary social need is usually a visit from family members. In their systematic review, Davies and Higginson (2005) claimed that cancer patients also seek psychosocial support from their caregivers. Therefore, support from both their families and caregiver teams were included in the questionnaire. And so were finances, which may be an important priority toward the end of life (Wijk & Grimby, 2008).

In the area of psychological needs, aside from a chance to share one's emotions, attention was also paid to needs related to adaptation to disease and acceptance of one's situation. Wijk and Grimby (2008) stressed the need to be free to express emotions, talk about them, and feel safe toward the end of life. Therapeutic interviews with patients and venting their emotions may reduce anxiety and fear. Yet, the questionnaire cannot be used to assess patients' mental health, anxiety, and depression. To determine the levels of anxiety and depression in palliative patients, another, already existing, tool should be used, such as the HADS (Holtom & Barraclough, 2000; Mitchell et al., 2010).

Another important studied area was that of needs related to autonomy. Toward the end of life, the need for appreciation and self-esteem becomes increasingly important. Autonomy is defined as the ability to direct, govern, and influence everyday life by one's own rules and ideas. This includes a capability to organize one's life, make one's own decisions, understand one's situation, and develop and implement plans (Scott et al., 2003).

An integral part of care is supporting the maintenance of independence, with respect to the illness, as much and for as long as possible, and of control over one's life, as well as of a chance to make decisions about oneself and one's care (McIllmurray et al., 2003). Also important is self-actualization through daily activities (Liang et al., 1990).

Situational needs were included among the spiritual needs grouped into the domain "meaning of life and reconciliation" (Kellehear, 2000), the aim of which was finding meaning and a goal in life, seeking hope and reassurance. The task is to find the meaning of life, gain hope, and maintain a social role within the setting of a progressive disease. Patients need help in coping with changes within their body or changes in the way they perceive them (McIllmurray et al., 2003). At the top of the hierarchy of needs are the need for self-actualization and the metaphysical needs that are specific toward the end of life. Frankl (1959) referred to these needs as the search for meaning. If this is unmet, existential frustration occurs.

A special domain was that of religious needs, involving spiritual support, ceremonies, and pastoral visits. Given the fact that the Czech Republic is an atheistic country (Nešpor, 2012), the spiritual dimension of needs had to be divided into two domains ("religious needs" and "meaning of life and reconciliation"). The reason was that religious needs were markedly less important than needs related to the search for meaning and reconciliation. According to the pilot survey, this greatly contributed to a lower score for spiritual needs (Bužgová et al., 2013). The lesser importance attributed to religious needs was

also problematic when assessing the goodness of fit between the models and the data using confirmatory factor analysis. Therefore, the domain was eliminated from model 4.

Construct validity was confirmed by a correlation between selected domains of the PNAP, EORTC QLQ-C30, and HADS. In the satisfaction scale, most domains were found to correlate with selected domains of both the EORTC QLQ-C30 and HADS. In particular, there was an association between quality of life and unmet needs. In the importance scale, there was a significant but weak correlation for only 10 out of 19 tested variables.

One drawback of the use of the PNAP instrument may be the burden on health professionals or the patients themselves involved in filling out the questionnaires. On average, a questionnaire takes 45 minutes to complete. Based on a systematic search of needs assessment instruments, Wen and Gustafson (2004) reported a completion time of up to 43 minutes, while Osse et al. (2000) reported 20–45 minutes. Similarly, Richardson et al. (2005) stated potential barriers to the use of assessment tools—namely, training of health professionals who carry out assessments and the time required to complete assessments.

Further testing of the instrument should focus on the use of the PNAP in other Central European countries with similar sociocultural conditions as well as its use in clinical practice.

CONCLUSION

The results of testing of the psychometric properties of the PNAP questionnaire showed at least satisfactory validity and reliability. The instrument can be used to assess the needs of palliative care patients, particularly those in Central European countries. Needs assessment is an important tool for understanding patients' priorities and serves as a basis for planning individualized care.

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REFERENCES

Aaronson, N., Alonso, J., Burnam, A., et al. (2002). Assessing health status and quality-of-life instruments: Attributes and review criteria. *Quality of Life Research*, 11, 193–205.

- Barrett, P. (2007). Structural equation modeling: Adjudging model fit. *Personality and Individual Differences*, 42, 815–824.
- Bonevski, B., Sanson-Fisher, R., Girgis, A., et al. (2000). Evaluation of an instrument to assess the needs of patients with cancer. *Cancer*, 88, 217–225.
- Bužgová, R., Hajnová, E. & Sikorová, L. (2013). Pilotní testování dotazníku PNAP „Hodnocení potřeb pacientů v paliativní péči.“ *Ošetrovatelství a Porodní Asistence*, 4, 628–633.
- Carlsion, M.D., Morrison, R.S. & Bradley, E.H. (2008). Improving access to hospice care: Informing the debate. *Journal of Palliative Medicine*, 11, 438–443.
- Coyle, N., Goldstein, M.L., Passik, S., et al. (1996). Development and validation of a patient needs assessment tool (PNAT) for oncology clinicians. *Cancer Nursing*, 19, 81–92.
- Crooks, D.L., Whelan, T.J., Reyno, L., et al. (2004). The Initial Health Assessment: An intervention to identify the supportive care needs of cancer patients. *Supportive Care in Cancer*, 12, 19–24.
- Cull, A., Stewart, M. & Altman, D.G. (1995). Assessment of and intervention for psychosocial problems in routine oncology practice. *British Journal of Cancer*, 72, 229–235.
- Currow, D.C., Agar, M., Sanderson, C., et al. (2008). Populations who die without specialist palliative care: Does lower uptake equate with unmet need? *Palliative Medicine*, 22, 43–50.
- Davidson, P., Cockburn, J., Daly, J., et al. (2004). Patient-centered needs assessment: Rationale for a psychometric measure for assessing needs in heart failure. *The Journal of Cardiovascular Nursing*, 19, 164–171.
- Davies, E. & Higginson, I.J. (2005). Systematic review of specialist palliative day care for adults with cancer. *Supportive Care in Cancer*, 13, 607–627.
- Deeken, J.F., Taylor, K.L., Mangan, P., et al. (2003). Care for the caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management*, 26, 922–953.
- Diwan, S. & Moriarty, D.G. (1995). A conceptual framework for identifying unmet health care needs of community dwelling elderly. *The Journal of Applied Gerontology*, 14, 47–63.
- Edmonds, P., Karlsen, S., Khan, S., et al. (2001). A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. *Palliative Medicine*, 15, 287–295.
- Emanuel, L.L., Alpert, H.R. & Emanuel, E.E. (2001). Concise screening questions for clinical assessments of terminal care: The needs near the end-of-life care screening tool. *Journal of Palliative Medicine*, 4, 465–474.
- Ewing, G. & Grande, G. (2013). Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study. *Palliative Medicine*, 27, 244–256.
- Fayers, P.M., Aaronson, N.K., Bjordal, K., et al. (2001). *The EORTC QLQ-C30 scoring manual*, 3rd. ed. Brussels: European Organisation for Research and Treatment of Cancer.
- Feeny, D., Farris, K., Côté, I., et al. (2005). A cohort study found that the RAND-12 and Health Utilities Index Mark 3 demonstrated construct validity in high-risk primary care patients. *Journal of Clinical Epidemiology*, 58, 138–141.
- Fitzsimons, D., Mullan, D., Wilson, J.S., et al. (2007). The challenge of patients' unmet palliative care needs in

- the final stages of chronic illness. *Palliative Medicine*, 21, 313–322.
- Fortner, B., Okon, T., Schwartzberg, L., et al. (2003). The Cancer Care Monitor: Psychometric content evaluation and pilot testing of a computer administered system for symptom screening and quality of life in adult cancer patients. *Journal of Pain and Symptom Management*, 26, 1077–1092.
- Frankl, V. (1959). *Man's search for meaning*. New York: Random House.
- Ganz, P.A., Schag, C.A., Lee, J.J., et al. (1992). The CARES: A generic measure of health-related quality of life for patients with cancer. *Quality of Life Research*, 1, 19–29.
- Gates, M.F., Lackey, N.R. & White, M.R. (1995). Needs of hospice and clinic patients with cancer. *Cancer Practice*, 3, 226–232.
- Grimshaw, J.M., Winkens, R.A., Shirran, L., et al. (2005). Interventions to improve outpatient referrals from primary care to secondary care. *The Cochrane Database of Systematic Reviews*, 20, 1–55.
- Holtom, N. & Barraclough, J. (2000). Is the Hospital Anxiety and Depression Scale (HADS) useful in assessing depression in palliative care? *Palliative Medicine*, 14, 219–220.
- Hooper, D., Coughlan, J. & Mullen, MR. (2008). Structural equation modeling: Guidelines for determining model fit. *The Electronic Journal of Business Research Methods*, 6, 53–60.
- Hu, L & Bentler, P.M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal*, 6, 1–55.
- Kellehear, A. (2000). Spirituality and palliative care: A model of needs. *Palliative Medicine*, 14, 149–155.
- Liang, L.P., Dunn, S.M., Gorman, A., et al. (1990). Identifying priorities of psychosocial need in cancer patients. *British Journal of Cancer*, 62, 1000–1003.
- Lidstone, V., Butters, E., Seed, P.T., et al. (2003). Symptoms and concerns amongst cancer outpatients: Identifying the need for specialist palliative care. *Palliative Medicine*, 17, 588–595.
- McIllmurray, M.B., Francis, B., Harman, J.C., et al. (2003). Psychosocial needs in cancer patients related to religious belief. *Palliative Medicine*, 17, 49–54.
- Mitchell, A.J., Meader, N. & Symonds, P. (2010). Diagnostic validity of the Hospital Anxiety and Depression Scale (HADS) in cancer and palliative settings: A meta-analysis. *Journal of Affective Disorders*, 126, 335–348.
- Nešpor, Z.R. (2012). Náboženství a ateismus v současné české společnosti ve světle statistických a sociologických výzkumů. *Salve—Revue pro Teologii a Duchovní Život*, 22, 7–20.
- Osse, B.H., Vernooij-Dassen, M.J., de Vree, B.P., et al. (2000). Assessment of the need for palliative care as perceived by individual cancer patients and their families: A review of instruments for improving patient participation in palliative care. *Cancer*, 88, 900–911.
- Osse, B.H., Vernooij-Dassen, M.J., Schadé, E., et al. (2007). A practical instrument to explore patients' needs in palliative care: The Problems and Needs in Palliative Care Questionnaire, short version. *Palliative Medicine*, 21, 391–399.
- Peterson, R.A. (1994). A meta-analysis of Cronbach's coefficient alpha. *Journal of Consumer Research*, 21, 381–391.
- Richardson, A., Sitzia, J., Brown, V., et al. (2005). *Patients' needs assessment tools in cancer care: Principles and practice*, 1st ed. London: King's College London.
- Sanson-Fisher, R., Girgis, A., Boyes, A., et al. (2000). The unmet supportive care needs of patients with cancer: Supportive Care Review Group. *Cancer*, 88, 226–237.
- Scott, P.A., Välimäki, M., Leino-Kilpi, H., et al. (2003). Perceptions of autonomy in the care of elderly people in five European countries. *Nursing Ethics*, 10, 28–38.
- Sepúlveda, C., Marlin, A., Yoshida, T., et al. (2002). Palliative care: The World Health Organization's global perspective. *Journal of Pain and Symptom Management*, 24, 91–96.
- Soothill, K., Morris, S.M., Harman, J., et al. (2001). The significant unmet needs of cancer patients: Probing psychosocial concerns. *Supportive Care in Cancer*, 9, 597–605.
- Steiger, J.H. (2007). Understanding the limitations of global fit assessment in structural equation modeling. *Personality and Individual Differences*, 42, 893–898.
- Streiner, D.L. & Norman, G.R. (2003). *Health measurement scales: A practical guide to their development and use*, 3rd ed. New York: Oxford University Press.
- Tamburini, M., Gangeri, L., Brunelli, C., et al. (2000). Assessment of hospitalised cancer patients' needs by the Needs Evaluation Questionnaire. *Annals of Oncology*, 11, 31–37.
- Terwee, C.B., Bot, S.D., de Boer, M.R., et al. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology*, 60, 34–42.
- Thomas, C., Soothill, K., McIllmurray, M., et al. (2001). *What are the psychosocial needs of cancer patients and their main carers? A study of user experience of cancer services with particular reference to psychosocial need*. Lancaster, England: Lancaster University, The Institute for Health Research.
- Tomáňová, M. & Bóriková, I. (2008). *Potreby v ošetrovatelstve*, 1 vyd. Martin: Osveta.
- Waller, A., Girgis, A., Currow, D., et al. (2008). Development of the palliative care needs assessment tool (PC-NAT) for use by multidisciplinary health professionals. *Palliative Medicine*, 22, 956–964.
- Waller, A., Girgis, A., Lecathelinais, C., et al. (2010). Validity, reliability and clinical feasibility of a needs assessment tool for people with progressive cancer. *Psycho-Oncology*, 19, 726–733.
- Ware, J.E. & Gandek, B. (1998). Methods for testing data quality, scaling assumptions, and reliability: The IQOLA Project approach. An International quality of life assessment. *Journal of Clinical Epidemiology*, 51, 945–952.
- Weissman, D.E. & Meier, D.E. (2011). Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from the Center to Advance Palliative Care. *Journal of Palliative Medicine*, 14, 17–23.
- Wen, K.Y. & Gustafson, D.H. (2004). Needs assessment for cancer patients and their families. *Health and Quality of Life Outcomes*, 2, 11.
- Wijk, H. & Grimby, A. (2008). Needs of elderly patients in palliative care. *The American Journal of Hospice & Palliative Care*, 25, 106–111.
- Wheaton, B., Muthén, B., Alwin, D.F., et al. (1977). Assessing reliability and stability in panel models. *Sociological Methodology*, 8, 84–136.
- Zigmond, A.S. & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychologica Scandinavia*, 67, 361–370.