Development of a tool to identify and assess psychosocial and spiritual needs in end-of-life patients: The ENP-E

Dolors Mateo-Ortega, PhD. (PSYC)^{1,2,3,4}, Joaquín T. Limonero, PhD. (PSYC)³, Jorge Maté-Méndez, PhD. (PSYC)^{3,5}, Elba Beas, C.N.A.¹, Jesús González-Barboteo, M.D., PhD.⁶, Elisabeth Barbero, SW, MSc⁷, Sara Ela, BA¹ and Xavier Gómez-Batiste, MD, PhD^{1,2}

¹The “Qualy” Observatory-WHO Collaborating Centre for Public Health Palliative Care Programs, Catalan Institute of Oncology, L’Hospitalet de Llobregat, Spain; ²Chair of palliative Care, University of Vic-Central University of Catalonia, Vic, Spain; ³Research Group on Stress and Health, Faculty of Psychology, Autonomous University of Barcelona, Bellaterra, Spain; ⁴Palliative Care Unit, Consorci Sanitari de Terrassa, Terrassa, Spain; ⁵Psychoncology Unit, Catalan Institute of Oncology, L’Hospitalet de Llobregat, Spain; ⁶Palliative Care Unit, Catalan Institute of Oncology, L’Hospitalet de Llobregat, Spain and ⁷Social Work Unit, Catalan Institute of Oncology, L’Hospitalet de Llobregat, Spain

Background

Most screening instruments to detect emotional distress in cancer patients differentiate between those with and without depression or anxiety. Clinicians are obliged to use instruments that only assess suffering indirectly.

Aims

To develop an instrument to better assess and monitor psychosocial and spiritual needs and emotional distress.

Methods

The scale was developed through a seven-stage process:

Results

Results PHASE 1: Content validation

Professionals and Patients made two specific recommendations: 1) reducing the number of questions, 2) changing the answering format to a Likert-type scale

Results PHASE 2: Construct validation

It was performed by 129 patients. The sample was equally divided between men (n=73) and women (n=76). The median age was 72 (range, 33 to 93) for men and 73 (43-93) for women. All patients had advanced cancer.

	Mean score on scale if this factor is removed	Scale variance if this factor is removed	Correlation: Factor/corrected total	Multiple correlation squared	Cronbach's alpha if factor removed
B1: How do you feel?	250.55	410.800	0.513	0.465	0.713
B2: Are you sad?	250.69	390.940	0.635	0.592	0.698
B3: Are you nervous?	250.67	430.020	0.330	0.402	0.735
B4: How are you handling this situation?	250.37	420.047	0.455	0.384	0.719
B5: Do you speak openly with your family about your illness?	250.68	450.119	0.182	0.143	0.755
B6: DO you believe you need to know more about your illness?	260.53	460.019	0.180	0.150	0.751
B7A: Do you feel cared for/supported by your family members?	260.96	460.673	0.304	0.257	0.737
B7B: Do you feel cared for/supported by your friends?	260.41	430.215	0.357	0.199	0.731
B8: In general, do you feel satisfied with what you've done during your life?	260.54	460.076	0.240	0.223	0.742
B9: Do you feel at peace?	260.61	460.703	0.199	0.181	0.746
B10: Do you believe your life has meaning?	260.23	400.584	0.563	0.435	0.706
B11: Do your beliefs and values help you in this situation?	260.12	410.456	0.452	0.349	0.719
B12: To summarize, taking into account what we've discussed: how would you rate your overall well-being?	250.57	430.914	0.423	0.293	0.725

Conclusions

The ENP-E provides data on a range of clinical aspects, thus offering relevant information to individualize patient care. Also, it can be administered repeatedly to provide current information on patients' level of emotional distress, which can be evaluated longitudinally to determine the influence of healthcare interventions over time on patients' psychosocial needs.

The ENP-E tool

PSYCHOSOCIAL AND SPIRITUAL NEEDS OF
END-OF-LIFE PATIENTS QUESTIONNAIRE (ENP-E)

A) EVALUATION OF PSYCHOSOCIAL NEEDS (questions for the patient)
We are going to ask you a series of questions about how you feel, think, and about the activities you have been doing recently:

QUESTIONS

Val ue

1

How are you feeling (mentally)?

☐ Not explored⁰ ☐ Very bad⁵ ☐ Bad⁴ ☐ OK³ ☐ Good² ☐ Very good¹

2

Are you sad?

☐ Not explored⁰ ☐ Not at all⁵ ☐ A little⁴ ☐ Neither a lot nor a little³ ☐ Quite a bit² ☐ Very much¹

3

Are you nervous?

☐ Not explored⁰ ☐ Not at all⁵ ☐ A little⁴ ☐ Neither a lot nor a little³ ☐ Quite a bit² ☐ Very much¹

4

How are you handling your situation?

☐ Not explored⁰ ☐ Very badly⁵ ☐ Badly⁴ ☐ OK³ ☐ Well² ☐ Very well¹

5

Do you speak openly with your family about your illness?

☐ Not explored⁰ ☐ Not at all⁵ ☐ A little⁴ ☐ Neither a lot nor a little³ ☐ Quite a bit² ☐ Very much¹

6

Do you believe you need to know more about your illness?

☐ Not explored⁰ ☐ No¹ ☐ A little more² ☐ Indifferent³ ☐ Quite a bit more⁴ ☐ A lot more⁵

7a

Do you feel cared for/supported by your family members?

☐ Not explored⁰ ☐ Not at all⁵ ☐ A little⁴ ☐ Neither a lot nor a little³ ☐ Quite a bit² ☐ Very much¹

7b

Do you feel cared for/supported by your friends?

☐ Not explored⁰ ☐ Not at all⁵ ☐ A little⁴ ☐ Neither a lot nor a little³ ☐ Quite a bit² ☐ Very much¹

8

In general, do you feel satisfied with what you've done during your life?

☐ Not explored⁰ ☐ Not at all⁵ ☐ A little⁴ ☐ Neither a lot nor a little³ ☐ Quite a bit² ☐ Very much¹

9

Do you feel at peace? (no regrets or feelings of guilt)

☐ Not explored⁰ ☐ Not at all⁵ ☐ A little⁴ ☐ Neither a lot nor a little³ ☐ Quite a bit² ☐ Very much¹

10

Do you believe your life has meaning?

☐ Not explored⁰ ☐ No⁵ ☐ A little⁴ ☐ Neither a lot nor a little³ ☐ Quite a bit² ☐ Very much¹

B) EXPLORATION OF WORRIES (Questions for the patient)
Keeping in mind everything we have talked about,
How worried are you about the following aspects of your life?:

13a

Financial

☐ Not explored⁰ ☐ Not at all¹ ☐ A little² ☐ Neither a lot nor a little³ ☐ Quite a bit⁴ ☐ Very much⁵

13b

Family

☐ Not explored⁰ ☐ Not at all¹ ☐ A little² ☐ Neither a lot nor a little³ ☐ Quite a bit⁴ ☐ Very much⁵

13c

Emotional

☐ Not explored⁰ ☐ Not at all¹ ☐ A little² ☐ Neither a lot nor a little³ ☐ Quite a bit⁴ ☐ Very much⁵

13d

Spiritual

☐ Not explored⁰ ☐ Not at all¹ ☐ A little² ☐ Neither a lot nor a little³ ☐ Quite a bit⁴ ☐ Very much⁵

13e

Physical discomfort

☐ Not explored⁰ ☐ Not at all¹ ☐ A little² ☐ Neither a lot nor a little³ ☐ Quite a bit⁴ ☐ Very much⁵

13f

Is there anything else that you consider important that worries you?

☐ No other worries

How much does this worry you?

☐ Yes, specify: _____

☐ Not explored⁰ ☐ Not at all¹ ☐ A little² ☐ Neither a lot nor a little³ ☐ Quite a bit⁴ ☐ Very much⁵

RESULTS SECTION B

HAS THE PATIENT EXPRESSED ANY WORRIES?

☐ No
☐ Yes

C) EXTERNAL SIGNS OF EMOTIONAL DISTRESS (ESD) (to be completed by the interviewer)
Rate the extent to which the following ESDs are evident (Items 14a to 14f):
0 = "Not present at all" to 10 = "totally present"

14a

Facial expression and behaviour (visible signs of sadness, fear, anger, nervousness...)

14b

Isolation (mutism, request to lower the blinds, refusal to accept visits, lack of hobbies/pastimes, lack of communication...)

14c

Demand for company/attention (constant complaints)

14d

Alterations in night-time behaviour (insomnia, nightmares, unjustified requests for rescue medication, complaints...)

14e

Other signs (specify):

14f

Provide an overall assessment of the intensity of emotional distress in this patient

(0-10):

RESULTS SECTION C

DOES THIS PATIENT PRESENT EXTERNAL SIGNS OF EMOTIONAL DISTRESS?

☐ No
☐ Yes

Sections

ENP-E RESULTS AND DIAGNOSIS

A

Questions for the patient

Questions 1 to 12
Total value (sum)

☐ Unable to explore all of the questions. Recommendation: examine the unanswered questions at the next intervention and then re-evaluate the patient when all questions have been answered.

☐ <26 No complex psychosocial needs detected. Recommendation: monitor the patient.

☐ ≥26 and < 28. Borderline cases. Recommendation: explore the patient's needs in greater depth, taking into account responses to the key questions, any worries expressed, and the presence of external signs of distress to determine the need for specialized care.

☐ ≥28 and ≤30: Moderate alert for complex needs. Recommendation: assess for specialized intervention.

☐ >30 and ≤33: High alert for complex needs. Recommendation: assess for specialized intervention.

☐ >33: Severe alert for complex needs. Recommendation: assess for specialized intervention.

Key questions:
1, 2, 4, 10, 12.
Did the patient score
≥4 points on one or
more of these
questions? (not the
total score)

☐ No. No complex psychosocial needs detected. Please follow the described instructions for the total value (sum) of the ENP-E

☐ Yes, key question ≥4. Complex needs detected. Recommendation: assess for specialized intervention.

B

Professional assessment

Question 13.
Does the patient have
any worries?

☐ No. No complex psychosocial needs detected. Please follow the described instructions for the total value (sum) of the ENP-E

☐ Yes. Recommendation: initiate interventions to address the specific worries.

C

Professional assessment

Question 14
Are any external signs
of emotional distress
evident in this
patient?

☐ No. No complex psychosocial needs detected. Please follow the described instructions for the total value (sum) of the ENP-E

☐ Yes. Complex needs detected. Recommendation: assess for specialized intervention.

Contact Details: Dolors Mateo-Ortega dmateo@cst.cat