

Supplemental files

Supplementary Table 1

Supplementary Table 1: Items of the PNPC-sv patient form and corresponding percentages of answers provided by patients (n=1103)

Is this a problem?			More professional attention?*
'Yes' and 'Somewhat' (Valid %)	PNPC-sv item: patient form	Domain	'Yes, more' (Valid %)
80.8	Worrying about the future of my loved ones	Psychological issues	22.0
76.8	Fear of metastases	Psychological issues	20.6
76.8	Difficulty coping with the unpredictability of the future	Psychological issues	17.8
24.2	Insufficient information e.g. about the disease and its treatment	Need of information	15.9
58.3	Fear of physical suffering	Psychological issues	13.9
38.6	Extra expenditures because of the disease	Financial problems	13.7
83.2	Fatigue	Physical symptoms	13.6
28.1	Insufficient information on the end of life	Need of information	13.6
54.2	Experiencing loss of control over one's life	Autonomy	12.9
22.0	Insufficient information on physical activity	Need of information	11.9
31.4	Loss of income because of the disease	Financial problems	11.6
17.1	Insufficient information on nutrition	Need of information	11.5
64.0	Being dependent of others	Autonomy	11.3
67.0	Difficulties in continuing the usual activities	Autonomy	10.6
51.4	Difficulties to accept the disease	Spiritual issues	10.3
49.5	Prickling or numb sensation	Physical symptoms	10.1
48.6	Fear of death	Psychological issues	10.1
61.5	Pain	Physical symptoms	9.7
49.1	Difficulty to give tasks out of hands	Autonomy	9.7
42.1	Difficulties to be engaged usefully	Spiritual issues	9.0
46.0	Shortness of breath	Physical symptoms	8.6
47.0	Sleeping problems	Physical symptoms	8.4
46.9	Dry mouth	Physical symptoms	8.4
44.3	Difficulties to be avail for others	Spiritual issues	8.3
18.0	Information about places and agencies that provide help (and aids)	Need of information	8.3

46.0	Depressed mood	Psychological issues	7.7
39.3	(Nightly) sweating or hot flushes	Physical symptoms	7.6
33.7	Finding it difficult to talk about the disease, because of not wanting to burden others	Social issues	7.6
13.4	Difficulties in finding someone to talk to (confidant)	Social issues	7.1
38.4	Difficulties concerning the meaning of death	Spiritual issues	7.0
34.7	Sexual dysfunction	Psychological issues	6.1
33.1	Difficulties in showing emotions	Physical symptoms	6.1
37.5	Drowsiness	Physical symptoms	6.0
38.7	Lack of appetite	Physical symptoms	5.8
35.3	Cough	Physical symptoms	5.4
16.6	Problems in the relationship with life companion	Social issues	5.4
23.1	Experiencing too little support by others	Social issues	5.1
17.3	Difficulties in talking about the disease with life companion	Social issues	4.3
24.7	Itch	Physical symptoms	3.9
20.2	Finding others not receptive to talking about the disease	Social issues	3.6

*. Valid % includes the percentage of all patients that wanted more professional attention for a specific item, irrespective of whether they regarded the item a problem.

Supplementary Table 2

Supplementary Table 2: Items of the PNPC-sv relative form and corresponding percentages of answers provided by relatives (n=831)

Is this a problem?			More professional attention?*
'Yes' and 'Somewhat' (Valid %)	PNPC-sv item – relative form	Domain	'Yes, more' (Valid %)
88.3	Fear for physical suffering of the patient	Psychological issues	32.8
83.9	Fear of metastases	Psychological issues	29.3
48.1	Knowing what physical signs I should notice	Caregiving	27.5
79.3	Fear of an unpredictable future	Psychological issues	23.0
43.5	How I should handle the patient's pain	Caregiving	22.5
69.6	Fear of death	Psychological issues	20.1
31.0	Insufficient information regarding the end of life	Need of information	16.4
24.5	Lack of conversations with a healthcare provider about the situation without the patient present	General matters in providing assistance	15.8
25.8	Insufficient information about supportive care (psychological support, social work, etc.) for yourself	Need of information	14.4
32.3	Difficulties in making arrangements (last will and testament, insurance etc.).	Financial problems	13.8
24.6	Difficulties in getting access to help from agencies/professional organizations.	General matters in providing assistance	13.8
24.5	How I should deal with the patient's nourishment	Caregiving	13.7
46.6	Fear that the patient's personality has changed	Relationship with the patient	12.9
51.6	Fatigue	Physical symptoms	12.7
24.8	Insufficient information on physical activity of the patient	Need of information	12.7
60.5	Hope for the future	Spiritual issues	12.6
23.9	Insufficient information about disease and treatment	Need of information	12.4
34.5	Difficulties in talking about the disease with patient	Relationship with the patient	12.0
28.6	Extra expenditure because of the disease	Financial problems	12.0
48.9	Difficulties in showing emotions	Psychological issues	11.7
43.4	Sleeping problems	Physical symptoms	11.5
53.9	Accepting the patients disease	Spiritual issues	10.9
15.3	Information on nourishment	Need of information	10.7
33.4	Doing heavy housework (changing beds etc.)	Daily activities	10.4
20.5	Difficulties fine-tuning the care of different professionals	General matters in providing assistance	10.4
42.6	Depressed mood	Psychological issues	10.3

17.3	Insufficient adjustment of hospital care to the home situation	General matters in providing assistance	9.7
45.8	The meaning of death	Spiritual issues	9.4
17.1	Lack of information in writing (inability to reread information)	General matters in providing assistance	8.7
25.7	How I can help the patient fill the days	Caregiving	8.5
29.3	How to find someone who, now and then, can take over the patient's care	Psychological issues	8.3
19.6	No longer experiencing any pleasure	Caregiving	8.3
34.6	Not wanting to leave the patient alone	Other matters	8.2
33.8	Changing the tasks and responsibilities in the family	Functional autonomy	8.1
33.5	Activities to relax	Functional autonomy	7.5
20.5	The contact with family, friends, neighbors, and colleagues	Social issues	6.6
26.6	Being dependent of others	Functional autonomy	6.5
34.4	Continuing to do the thing I do for others	Functional autonomy	6.4
24.7	Sexuality in my relationship with the patient	Relationship with the patient	6.1
19.6	My feelings of not being supported by others	Social issues	5.8
22.9	That the patient is in denial of the severity of the situation	Other matters	5.7
30.7	Feelings of guilt	Psychological issues	5.3
8.4	Disagreement (with patient or family) about the treatment the patient should have	Other matters	2.2
7.0	Feeling abandoned by the people in my environment	Social issues	1.5

*. Valid % includes the percentage of all relatives that wanted more professional attention for a specific item, irrespective of whether they regarded the item a problem.

Supplementary Table 3

Supplementary Table 3: Spearman's rank correlation coefficients (r_s) used to evaluate the possible relationship between the patients' characteristics and the total score of unmet needs and the scores of unmet needs per domain

	Sum score	Autonomy	Need of information	Physical symptoms	Spiritual issues	Financial problems	Social issues	Psychological issues
	r_s	r_s	r_s	r_s	r_s	r_s	r_s	r_s
Age	-.093**	-.011	-.122**	-.080*	.006	-.142**	-.082**	-0.46
Gender (‘Male’/‘Female’)	.074*	-.002	.078*	.030	.033	.014	.048	.050
Marital status (‘Partner’/‘No partner’)	.082*	.046	.072*	.020	.032	.039	.059	.041
Educational level (‘Low’/‘Medium’/‘High’)	-.042	-.075*	.070*	-.031	-.105**	-.088**	-.076*	-.031
Nationality (‘Dutch’/‘not Dutch’)	.047	.013	.072*	.073*	.007	.017	.018	.027

*. Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Supplementary Table 4a

Supplementary Table 4a: Spearman's rank correlation coefficients (r_s) used to evaluate the possible relationship between the relatives' characteristics and the total score of unmet needs and the scores of unmet needs per domain

	Sum score	Caregiving	Physical symptoms	Relationship with the patient	Autonomy	Social issues	Psychological issues	Financial problems	Daily activities	Other matters	General matters in providing assistance	Spiritual issues	Need of information
	r_s	r_s	r_s	r_s	r_s	r_s	r_s	r_s	r_s	r_s	r_s	r_s	r_s
Age	-.121**	-.127**	.005	-.158**	-.079*	-.059	-.061	-.093*	-.005	-.128**	-.147**	-.027	-.094*
Gender (Male/Female)	-.022	-.052	.012	.019	.015	-.002	-.016	-.003	-.037	.026	-.015	.053	.037
Marital status (Partner/No partner)	.019	.050	-.011	.046	.010	.012	.002	-.006	.015	.060	.040	-.033	-.011
Educational level (Low/Medium/High)	.099**	.139**	.038	.072*	.078*	-.011	.061	.081*	.006	.105**	.138**	.046	.151**
Nationality (Dutch/not Dutch)	.063	.089*	.027	.058	.053	.054	.056	.028	.017	.009	.033	.064	.046

*. Correlation is significant at the 0.05 level (2-tailed).

** . Correlation is significant at the 0.01 level (2-tailed).



Supplementary Table 4b

Supplementary table 4b: Mean and standard deviations of multiple domain scores per category of the relatives' nature of relationship, and the results of the Kruskal-Wallis H test

Domains Subcategories	Mean scores	N	SD	H-Statistic	df	Sig.	Pairwise comparisons (Std. Test Statistic)	Adj. Sig.	Effect size
Total				7.90	3	.048*			
Spouse	11.95	553	16.29						
Son or daughter	13.84	127	17.57						
Other family member	8.57	36	17.31				2.78	.033*	.218
Friend	10.65	23	11.66						
Total	12.07	739	16.45						
Missing		92							
Caregiving				11.89	3	.008*			
Spouse	15.34	559	24.66						
Son or daughter	21.93	129	27.29				-3.07	.013*	-.117
Other family member	9.86	37	19.31						
Friend	19.17	24	27.33				2.70	.041*	.210
Total	16.32	749	25.11						
Missing		82							
General matters in providing assistance				15.06	3	.002*			
Spouse	9.97	547	19.56						
Son or daughter	19.74	128	29.13				-3.84	.001*	-.148
Other family member	10.29	35	21.89						
Friend	11.30	23	20.74						
Total	11.73	733	21.94						
Missing		98							
Relationship patient				9.04	3	.029*			
Spouse	9.96	557	21.48						
Son or daughter	16.02	129	26.96						
Other family member	8.08	33	22.10						
Friend	7.25	23	22.38						
Total	10.85	742	22.67						
Missing		89							
Physical symptoms				9.43	3	.024*			
Spouse	13.72	565	30.83						
Son or daughter	8.98	128	26.94						
Other family member	5.56	36	23.23						
Friend	4.17	24	20.41						
Total	12.22	753	29.68						
Missing		78							

*. Statistically significant differences between subcategories ($p < .05$).