Assessment of Needs of Hospitalized Cancer Patients with Advanced Cancer

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Abstract

Background: Needs assessment of patients with advanced cancer (ACPs) is essential for optimal care. This study evaluated the psychometric properties of the Needs Evaluation Questionnaire (NEQ) and assessed the supportive care needs of hospitalized ACPs with solid tumors.

Methods: The validated Greek version of the NEQ along with demographic and clinical data of 95 consecutive breast, colon and lung ACPs hospitalized in the University Hospital of Heraklion, Crete, Greece, were used to assess their supportive care needs. The NEQ score was subsequently rescaled to 0-100.

Results: NEQ displayed adequate psychometric properties in validity and reliability tests. The average number of needs reported was 8.4(4.1). Female and younger patients reported a higher score of unmet needs than their male (40.3 versus 30.0, p=0.005) and elder (40.1 versus 29.2, p=0.001) counterparts. Patients reported higher needs in receiving information about their future (73.7%), treatments (56.8%), examinations (51.6%) and for the need "*to speak with people who had the same experience*" (53.7%). In contrast, lower scores were observed in the assistance and treatments needs regarding *intimacy* (11.6%), "*better attention from nurses*" (15.8%), "*more help with eating, dressing, and going to the bathroom*" (18.9%). Lung ACPs reported more assistance and treatment needs than colon and breast ACPs (p<0.05).

Conclusions: ACPs reported many unmet needs, mainly informational, that were related to gender, age, and type of cancer. NEQ is a useful tool in everyday clinical practice for obtaining information for supportive care needs. Health care personnel has to address these needs for implementing effective patient-centered care.

Keywords: advanced cancer, needs assessment, needs evaluation questionnaire (NEQ), unmet needs

1. Introduction

The optimal supportive care of patients with advanced cancer (ACPs) aims to maximize the benefits of different treatments and interventions (Glare, 2013; Peppercorn et al., 2011). This can be achieved with effective communication between patients, their caregivers and health professionals, accurate assessment of patients' needs, alleviation of symptoms, improvement of everyday functionality and quality of life, and patients' satisfaction (Bredart et al., 2013; Abernethy, Wheeler, & Currow, 2010).

ACPs require high level supportive care (Harrison, Young, Price, Butow, & Solomon, 2009; Rainbird, Perkins, Sanson-Fisher, Rolfe, & Anseline, 2009), depending on age, gender, type of cancer, the setting of care, unmet expectations and the efficacy of the existing palliative care services (Schenker, Park, Maciasz, & Arnold, 2014; Ugalde, Aranda, Krishnasamy, Ball, & Schofield, 2012; Li & Girgis, 2006; Tamburini et al., 2003; Walsh, Donnelly, & Rybicki, 2000). Although the perceived needs' frequency and intensity varies, the percentage of ACPs with unmet requirements often reaches 95% over the course of the disease (Harrison et al., 2009; Rainbird et al., 2009). The inadequate recognition of patients' needs by health professionals has been associated with psychological distress, worse functional function, additional suffering, low level of patient satisfaction and

impaired quality of life (Edib, Kumarasamy, Binti Abdullah, Rizal, & Al-Dubai, 2016; Bužgová, Hajnová, Sikorová, & Jarošová, 2014).

Continuous, systematic and individualized needs assessment is the core point in planning ACPs care (Richardson, Medina, Brown, & Sitzia, 2007). This care usually focuses on the physical, psychological, social, sexual, spiritual, informational, financial and other daily living needs of patients and their important ones (Moghaddam, Coxon, Nabarro, Hardy, & Cox, 2016; Ugalde et al., 2012; Pearce, Coan, Herndon, Koenig, & Abernethy, 2012; Marcusen, 2010; Bahti, 2010; Harrison et al., 2009). Effective needs' assessment requires an in depth and increased patient's involvement. Patients' perceptions and views contribute to better identify the type of assistance required and adaptation of interventions according to ACPs' individual needs (Pearce et al., 2012; Carey et al., 2012; Elkin, Kim, Casper, Kissane, & Schrag, 2007). Many tools assessing the different and diverse supportive care needs of ACPs have been developed (Carlson, Waller, & Mitchell, 2012; Abernethy et al., 2010; Richardson et al., 2007). Some of them are quite specialized and extended, covering most of the ACPs needs. However, these tools often don't take into account the limited or non-existing palliative care services, the high workload and the reduced resources of Greek hospitals (Efstathiou, Ameen, & Coll, 2008). In such environments the optimum choice would be the implementation of short, easy-to-use questionnaires in the daily clinical practice in order to screen and document urgent or unmet needs.

Limited research on the unmet ACPs needs, especially regarding their psychological distress, symptom management, as well as the burden of caregivers, has been conducted in Greece (Govina et al., 2015; Alexopoulos, Koutsogiannou, Moratis, Mestousi & Jelastopulu, 2011; Mystakidou et al., 2006). Thus, the aim of the present study was the assessment of supportive care needs with the Greek version of Needs Evaluation Questionnaire in a group of hospitalized ACPs with solid tumors.

2. Methods

2.1 The Needs Evaluation Questionnaire (NEQ)

ACPs needs were assessed with the use of NEQ, a standardized self-administered questionnaire consisting of 23 dichotomous items originally in Italian language (Tamburini et al., 2003). It comprises eight different types of needs: informational concerning diagnosis and prognosis (items 1 and 2), informational concerning examinations and treatment (items 3 and 4), communicative (items 5-8) and relational needs (items 20-22), which constitute four distinct factors. Twelve additional single-item needs related to assistance and treatment (items from 9 to 13), structure related needs (item 14), financial aspects (items 15, 16) and needs for support (items 17-19, 23) complete the questionnaire. NEQ was mainly used in hospitalized Italian oncology patients (Annunziata, Muzzatti, Bidoli, & Veronesi, 2012; Romito, Corvasce, Montanaro, & Mattioli, 2011; Tamburini et al., 2003; Tamburini et al., 2000).

2.2 Translation of the NEQ

After obtaining the permission for using the NEQ, its translation and cultural adaptation was performed according to the Minimal Translation Criteria (Medical Outcomes Trust, 1997). Based on this procedure, two independent bilingual translators, native speakers of Greek with advanced knowledge of the Italian language, translated the questionnaire into Greek (forward translation). With the contribution of a third reviewer, a reconciliation meeting was conducted to develop a consensus version (reconciliated Greek version). This version was then back-translated by a native Italian speaker, not familiar with the original questionnaire. Using all the information from the two phases and after thorough discussion with translators and reviewers, the first author acting as adjudicator approved the final version of the NEQ. Translation and back translation did not reveal substantial problems and the research team solved very minor differences. As the last step of the translation procedure, a cognitive debriefing process was used for the cultural adaptation of the questionnaire (Medical Outcomes Trust, 1997). As part of the cultural adaptation process, the questionnaire was administered to five ACPs and in-depth interviews were implemented regarding the respondents' level of understanding of the questionnaire with the purpose of revealing inappropriately interpreted items and translation alternatives. The participants expressed their views regarding the clarity of each item, the relevance of the content to their situation, the comprehensiveness of the instructions and their ability to complete it on their own. They were also encouraged to make suggestions whenever necessary. The comments made by the participants were discussed in a debriefing session ending to the final Greek version of the NEQ.

2.3 Psychometric Validation of the NEQ

Test-retest reliability

Test-retest reliability was measured in 8 ACPs with an interval of one week. From the affirmative answers of the 23

needs (Yes=1, No=0) it became the aggregation and calculation of the total concentration for each patient's needs (range 0-23). The test-retest analysis did not reveal any significant change in the mean number of needs in the pre and post testing period of seven days (Wilcoxon signed ranks test: 9.38±5.53 vs. 9.63±5.98, respectively, p=0.414 and Spearman's correlation coefficient: r=0.994, p<0.001).

Reliability analysis

Out of the 95 ACPs, 91 patients fully completed the NEQ and four of them provided missing responses in four items (see Table 2 for missing data). The missing values were then replaced by the mode values in each of the four items. The reliability coefficient of Kuder - Richardson was also estimated giving an estimation of r20 equal to 0.752.

Validity

An exploratory factor analysis (EFA) was performed to determine the structure of the questionnaire and how the individual items grouped together. Principal component analysis (PCA) was used with and Varimax with Kaiser normalization as the rotation method (oblique). Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was estimated at 0.628 (middling/mediocre fit) and the Bartlett's test of sphericity was employed to determine the appropriateness of the dataset for factor analysis and to verify the degree of interrelation between the items (χ^2=454.5, d.f.=253, p<0.001). Eight factors (groups of needs) were found as reported by the developers of the NEQ (Tamburini et al., 2000), with eigenvalues ≥1.00 and 61.9% of total variance explained. A minimum loading criterion of 0.40 was adopted for scale items to be maintained in each factor.

2.4 Final Questionnaire

In the final questionnaire, in addition to NEQ, a number of demographic questions regarding the patients' gender, marital status, place of residence, year of birth, and education level were included. Clinical data including patient's disease, presence or absence of metastases, time of initial diagnosis, number of hospital admissions in the last two months and type of treatments were extracted from the medical files. Satisfaction with care was recorded in a scale from 0 (not satisfied) to 10 (very satisfied). The mean duration of completing the questionnaire was 10-15 minutes.

2.5 Participants

Ninety five consecutive breast, lung and colon ACPs cared for as inpatients (41.1%) or at the day clinic (58.9%) of the Department of Medical Oncology of the University Hospital of Heraklion, Crete, Greece, were enrolled between November 2007 - February 2008. The sample size was based on the number of in- and day clinic patients cared for, during the month preceding the research. They were randomly selected according to the number of the three common types of cancer of the two services (multistage proportional stratified probability sampling). The inclusion criteria were age over 18 years, ability to speak and write in Greek, treatment with at least one chemotherapy cycle or at least two months' time period from the disease's diagnosis and granting of informed consent. Patients completed the questionnaire only once, although most of them (73.4%) visited the hospital repeatedly during the study period.

2.6 Ethical Considerations

The study was approved by the Hospital's Ethical Committee and all patients were thoroughly informed about the aims of the study before completing the questionnaires.

2.7 Statistical Analysis

Data were analyzed with the use of the SPSS software (IBM SPSS Statistics for Windows, Version 23.0 Armonk, NY: IBM Corp). A normality test was performed of the total score of the needs according to the Blom's method (QQ plot), without revealing any declination. The frequencies of the descriptive characteristics of 95 cancer patients were estimated, while the mean levels of needs score were compared in these categories throughout the methods of Student t, Kruskal Wallis or Mann Whitney and Chi-square tests.

Each need (item or question) was separately coded into a binary variable (0=absence, 1=presence). A composite score was then calculated by adding up the number of individual needs (min 0 and max 23 needs), whereas the accumulation of greater than the median value (≥8 needs) was considered to be as a high frequency of needs. Following recent research, this score was subsequently rescaled to 0-100 to be more easily interpretable and understood, with higher values indicating higher level of needs (Linardakis et al., 2015).

3. Results

The 95 ACPs had a mean age equal to 59.8(11.9) years and a percentage of 36.8% were aged ≥66 years, 58.9% were females, 74.5% were married and 49% had primary or no formal education (Table 1). The diagnoses were

almost equally distributed among breast (n=32, 33.7%), lung (n=32, 33.7%) and colorectal cancer cases (n=31, 32.6%).

The overall mean score of patients' needs was 36.1(±17.9) and their mean number was equal to 8.4(±4.1) Females reported a higher score of unmet needs than males (40.3 versus 30.0, *p*=0.005) and more than 8 needs (high score) (60.7% versus 35.9%, *p*=0.022). In a similar way, younger ACPs (<66 years) reported a higher score of unmet needs than older patients (40.1 versus 29.2, *p*=0.001) and more than 8 needs (60.0% versus 34.3%, *p*=0.02). Furthermore, the group of "satisfied" (≥8/10) patients from the care provided (74.2%) had a lower mean score of needs than those "not satisfied" (30.6 versus 40.3, *p*=0.009) and less high number of needs (40.6% versus 75.0%, *p*=0.005). Concerning other variables, such as marital status, education, place of residence, cancer type and department of care, statistical significant differences between groups were not detected.

Patients reported higher levels of needs with regard to receiving information about their future condition (73.7%), treatments (56.8%), examinations (51.6%) and diagnosis (50.5%) (Table 2). In addition, their need "to *speak with people who had the same experience*" was also reported as high too (53.7%). In contrast, lower reported needs were observed in group assistance and treatments needs regarding "*better respect for my intimacy*" (11.6%), "*better attention from nurses*" (15.8%), "*more help with eating, dressing, and going to the bathroom*" (18.9%). By dividing patients into 2 subgroups (up to 65 and ≥66 years old) it was found that in both groups the most prevalent needs were informational (items 2 & 4 for younger patients and 2 & 3 for older), while the less frequently expressed need was for both groups the one for intimacy (item11). Significant differences were observed among younger patients in the 8 items of their needs (items 11-16, 22, 23).

Associations between the socio-demographic variables, the overall satisfaction with care and the type of cancer with the percentage of positive answers in at least one need for each group of ACPs are described in Table 3. Females reported more needs in assistance and treatment, support and relational domain of needs than males. Younger patients reported more needs for assistance and treatment, structure, financial and support domain of needs and less communicative need than the older ones. Patients living near the hospital revealed less examinations and treatment informative needs than those living in other cities/areas. Patients cared for in a oncology ward had more examination/treatment informative needs and more structure needs than those cared for in the day clinic. Patients who had five or more visits to hospital over the last two months had higher relational needs than the other two subgroups. Patients less satisfied with the care provided, declared more communicative, assistance and treatment and structure needs than patients who declared satisfied. Finally, lung ACPs revealed more assistance and treatment needs than colon and breast ACPs (p<0.05).

Table 1. Descriptive characteristics, score and frequency of needs of the 95 cancer patients.

		n	%	Score of needs [a]	p-value [b]	Frequency of needs [a]		p-value [c]
				Mean (s.d.)		low %	high	
Total		95	-	36.1 (17.9)	-	49.5	50.5	-
Gender	*males*	39	41.1	30.0 (15.0)	0.005	64.1	35.9	0.022
	females	56	58.9	40.3 (18.7)		39.3	60.7	
Age, *years*	*up to 65*	60	63.2	40.1 (19.8)	0.001	40.0	60.0	0.020
	≥66	35	36.8	29.2 (11.4)		65.7	34.3	
	mean age (s.d.) [min-max]	59.8 (11.9) [33-77]						
Marital status	*married*	70	74.5	34.7 (17.4)		50.7	49.3	
	single	6	6.4	44.2 (25.3)	0.539	50.0	50.0	0.893
	divorced, widowed	18	19.1	38.9 (17.9)		44.4	55.6	
Education	*higher (college, universities)*	16	17.0	36.1 (22.4)		43.7	56.3	
	secondary school	32	34.0	39.3 (15.9)	0.318	40.6	59.4	0.251
	primary school or/and no education	46	49.0	33.2 (17.2)		58.7	41.3	
Place of residence	*near hospital*	53	55.8	36.8 (18.1)	0.642	41.5	58.5	0.100
	other cities/areas	42	44.2	35.1 (17.9)		59.5	40.5	
Site of care	*oncology ward*	39	41.1	37.5 (16.3)	0.530	51.3	48.7	0.836
	oncology day clinic	56	58.9	35.1 (19.1)		48.2	51.8	
Hospital visits during last two months	*one, two*	25	26.6	34.6 (13.6)		56.0	44.0	
	three, four	21	22.3	36.0 (21.9)	0.933	47.6	52.4	0.782
	five or more	48	51.1	36.9 (18.5)		47.9	52.1	
Degree of satisfaction from care [d]	*<8*	24	25.8	40.3 (16.2)	0.009	25.0	75.0	0.005
	≥8	69	74.2	30.6 (18.8)		59.4	40.6	
Type of cancer	*lung*	32	33.7	36.5 (18.1)		46.9	53.1	
	colon/rectum	31	32.6	34.2 (18.1)	0.754	54.8	45.2	0.767
	breast	32	33.7	37.4 (18.2)		46.9	53.1	

s.d., standard deviation

[a] Score from 0 to 100; higher score means more needs. The overall mean number of needs was 8.4 (±4.1). The cut-off value of low or high frequency was the median value of needs (≥8 needs). [b] Student t and Kruskall Wallis tests were used. Post hoc comparisons were tested by Mann Whitney test (no significant differences were found). [c] Chi-square tests. [d] Satisfaction from care was recorded in a scale from 0 (not satisfied) to 10 (very satisfied). Eight corresponds to median value.

Table 2. Answers distribution of Needs Evaluation Questionnaire (NEQ) in 95 cancer patients

Item		Yes, %			Missing data (%)	Higher/lower needs [a]	
		Total	Age				
			up to 65	≥66			
1	*I need more information about my diagnosis*	50.5	48.3	54.3	-	5	↑
2	*I need more information about my future condition*	73.7	68.3	82.9	-	1	↑
3	*I need more information about the exams I am undergoing*	51.6	46.7	60.0	-	4	↑
4	*I need more explanations of treatments*	56.8	58.3	54.3	-	2	↑
5	*I need to be more involved in the therapeutic choices*	30.5	31.7	28.6	-	15	
6	*I need clinicians and nurses to give me more comprehensible information*	33.7	38.3	25.7	-	14	
7	*I need clinicians to be more sincere with me*	42.1	43.3	40.0	-	8	
8	*I need to have a better dialogue with clinicians*	43.2	46.7	37.1	-	7	
9	*I need my symptoms (pain, nausea, insomnia, etc.) to be better controlled*	40.0	46.7	37.1	1.1	10	
10	*I need more help with eating, dressing, and going to the bathroom*	18.9	21.7	14.3	-	21 ↓	
11	*I need better respect for my intimacy*	11.6	16.7 [b]	2.9	-	23 ↓	
12	*I need better attention from nurses*	15.8	21.7 [b]	5.7	-	22 ↓	
13	*I need to be more reassured by the clinicians*	33.7	41.7 [b]	20.0	1.1	13	
14	*I need better services from the hospital (bathrooms, meals, cleaning)*	48.4	58.3 [b]	31.4	-	6	
15	*I need to have more economic insurance information (tickets, invalidity, etc.) in relation to my illness*	18.9	26.7 [b]	5.7	-	20 ↓	
16	*I need economic help*	38.9	55.0 [b]	11.4	1.1	11	
17	*I need to speak with a psychologist*	22.1	25.0	17.1	-	19 ↓	
18	*I need to speak with a spiritual advisor*	22.1	26.7	14.3	-	18	
19	*I need to speak with people who have the same experience*	53.7	51.7	57.1	-	3	↑
20	*I need more reassured from my relatives*	22.1	25.0	17.1	-	17	
21	*I need to feel more useful within my family*	35.8	40.0	28.6	1.1	12	
22	*I need to feel less abandoned*	25.3	35.0 [b]	8.6	-	16	
23	*I need to receive less commiseration from other people*	40.0	56.3 [b]	17.1	-	9	

[a] With arrow are presented the five higher (↑) or lower (↓) needs according to percentages.

[b] Significant differences between age groups (p<0.05, Chi-square tests).

Table 3. Classification of needs (in groups) in relation to descriptive characteristics of the 95 cancer patients

Characteristic	Subgroup	Informational Diagnosis/prognosis % [a]	mean [b]	s.d.	Informational Exams/treatment %	mean	s.d.	Communicative %	mean	s.d.	Assistance and treatment %	mean	s.d.	Structure %	mean	s.d.	Financial aspects %	mean	s.d.	Support %	mean	s.d.	Relational %	mean	s.d.
Gender	males	84.6	1.2	0.7	69.2	1.1	0.8	74.4	1.3	1.1	53.8[c]	0.9[c]	1.1	46.2	0.5	0.5	43.6	0.6	0.7	64.1	0.9[c]	0.9	38.5[c]	0.5[c]	0.6
	females	75.0	1.3	0.8	71.4	1.1	0.8	78.6	1.6	1.3	76.8	1.1	1.1	50.0	0.5	0.5	42.9	0.6	0.8	82.1	1.7	1.1	64.3	1.1	1.0
Age, years	up to 65	75.0	1.2	0.8	66.7	1.1	0.9	75.0	1.6[c]	1.4	75.0[c]	1.4	1.2	58.3[c]	0.6	0.5	60.0[c]	0.8	0.8	80.0	1.6[c]	1.1	60.0	1.0	1.0
	≥66	85.7	1.4	0.7	77.1	1.1	0.8	80.0	1.3	0.9	54.3	0.8	0.9	31.4	0.3	0.5	14.3	0.2	0.5	65.7	1.1	0.9	42.9	0.5	0.7
Marital status	married	77.5	1.2	0.8	69.0	1.1	0.8	74.6	1.4	1.2	64.8	1.2	1.2	49.3	0.5	0.5	43.7	0.6	0.7	74.6	1.3	1.0	52.1	0.8	1.0
	single	83.3	1.2	0.8	50.0	0.7	0.8	83.3	2.2	1.7	83.3	1.8	1.3	83.3	0.8	0.4	50.0	1.0	1.0	66.7	2.0	1.7	50.0	0.7	0.8
	divorced, widowed	88.3	1.4	0.8	83.3	1.2	0.7	72.2	1.8	1.3	72.2	1.1	0.9	33.3	0.3	0.5	38.9	0.5	0.7	77.8	1.7	1.3	61.1	0.9	0.9
Education	higher (college, universities)	75.0	1.3	0.9	56.3	0.8	0.8	68.8	1.6	1.4	68.8	1.5	1.4	37.5	0.7	0.5	62.5	0.7	0.7	62.5	1.3	1.3	50.0	0.8	0.9
	secondary school	87.5	1.3	0.7	65.6	1.0	0.8	84.4	1.6	1.2	75.0	1.3	1.1	53.1	0.5	0.5	37.5	0.8	0.9	84.4	1.6	1.0	56.3	1.0	1.0
	primary school or/and no education	73.9	1.2	0.8	78.3	1.2	0.8	71.7	1.4	1.3	41.3	1.0	1.1	37.0	0.4	0.5	37.0	0.4	0.6	71.7	1.3	1.1	52.2	0.7	0.8
Place of residence	Near hospital	77.4	1.2	0.8	60.4[c]	1.0	0.9	81.1	1.5	1.2	71.7	1.3	1.2	47.2	0.5	0.5	43.4	0.5	0.7	73.6	1.4	1.2	54.7	0.9	1.0
	Other cities/areas	81.0	1.2	0.8	83.3	1.2	0.7	71.4	1.4	1.3	61.9	1.0	1.1	50.0	0.5	0.5	42.9	0.6	0.8	76.2	1.3	1.0	52.4	0.7	0.9
Department of care	Oncology ward	82.1	1.3	0.8	84.6[c]	1.3[c]	0.7	76.9	1.7	1.3	64.1	1.2	1.2	64.1[c]	0.6[c]	0.5	46.2	0.6	0.7	74.4	1.3	1.1	46.2	0.6	0.7
	Oncology day clinic	76.8	1.2	0.8	60.7	0.9	0.8	76.8	1.4	1.2	69.9	1.2	1.1	37.5	0.4	0.5	41.1	0.6	0.8	75.0	1.4	1.1	58.9	0.7	1.0
Hospital visits during last two months	one, two	76.0	1.2	0.8	84.0	1.2	0.7	72.0	1.4	1.2	76.0	1.2	1.0	48.0	0.5	0.5	40.0	0.5	0.7	72.0	1.3	1.0	48.0[c]	0.7	0.9
	three, four	81.0	1.2	0.7	66.7	1.0	0.8	81.0	1.6	1.3	76.2	1.4	1.3	52.4	0.5	0.5	52.4	0.8	0.8	76.2	1.2	1.0	28.6	0.6	1.1
	five or more	79.2	1.3	0.8	66.7	1.1	0.9	77.1	1.5	1.2	58.3	1.1	1.1	47.9	0.5	0.5	41.7	0.5	0.7	77.1	1.5	1.1	52.2	1.0	0.9
Degree of satisfaction from care	<8	75.0	1.3	0.8	79.2	1.3	0.8	87.5	2.2[c]	1.3	83.3[c]	1.6[c]	1.2	79.2[c]	0.8[c]	0.4	54.2	0.8	0.8	83.3	1.7	1.2	58.3	1.0	1.0
	≥8	79.7	1.2	0.8	68.1	1.0	0.8	73.9	1.3	1.1	60.9	1.1	1.1	37.7	0.4	0.5	40.6	0.5	0.7	71.0	1.2	1.0	52.2	0.8	0.9
Cancer site	lung	84.4	1.3	0.7	62.5	0.9	0.8	78.1	1.6	1.3	78.1[c]	1.4	1.2	46.9	0.5	0.5	53.1	0.7	0.7	68.8	1.3	1.1	53.1	0.8	0.9
	colon/rectum	77.4	1.3	0.8	80.6	1.3	0.8	80.6	1.5	1.2	48.4	0.9	1.2	51.6	0.5	0.5	29.0	0.4	0.6	67.7	1.3	1.2	48.4	0.7	0.8
	breast	75.0	1.2	0.8	68.8	1.0	0.8	71.9	1.4	1.2	75.0	1.3	1.0	46.9	0.5	0.5	46.9	0.7	0.8	87.5	1.6	1.0	59.4	1.0	1.0

s.d., standard deviation
[a] Percentage of patients with at least one need. Chi-square tests. [b] Mann Whitney or Kruskal Wallis tests were used. [c] p<0.05.

4. Discussion

The present study has translated and validated the Greek version of the NEQ and subsequently used it to assess the needs of hospitalized ACPs in a large tertiary regional Hospital. The NEQ displayed adequate psychometric properties and was easily handled both by the health professionals and by the patients. ACPs have considerable level of supportive care needs, arising from their disease and the therapeutical interventions provided (Rainbird et al., 2009; Bahti, 2010). The present findings have shown a mean number of needs equal to 8.4. Other authors have reported higher needs in a group of breast ACPs (Uchida et al., 2011), while in another group with mixed cancer population, lower number of needs was reported (Annunziata, Muzzatti, & Bidoli, 2010). Systematic reviews regarding unmet care needs have identified that ACPs have needs across multiple domains, while most prevalent have been those of physical, economic, informational, communicational, spiritual and psychological spectrum (Moghaddam et al., 2016; Harrison et al., 2009). High levels of unmet needs suggest that health professionals don't adequately recognize issues relevant to ACPs care (Elkin et al., 2007), or that patients may not request palliative care services (Schenker et al., 2014) or that the interventional procedures have limited effectiveness (Carey et al., 2012).

Over the last years there is growing interest to systematically explore patients' prevalent needs in routine clinical practice with the use of specific needs assessment tools (Carlson et al., 2012; Richardson et al., 2007). With these procedures, early implementation of palliative care, appropriate use of supportive care services and improvement of the patients' well-being can occur (Schenker et al., 2014; Glare, 2013; Peppercorn et al., 2011).

In a holistic patients-centered approach, demographic and clinical variables such as gender, age, as well as type of cancer should be taken into account (Kirkova, Rybicki, Walsh, & Aktas, 2012; Li & Girgis, 2006; Walsh et al., 2000). In the present study gender related differences of needs have been observed, with females expressing more needs than males. Females have required more effective care and reported more prevalent symptoms than males (Kirkova et al., 2012; Wessels et al., 2010). Younger ACPs reported higher number of unmet needs in many domains than the older ones. Previous studies have come to different conclusions. In particular, some studies have also shown that younger ACPs were more likely to have more symptoms, greater suffering and distress and probably more unmet needs (Walsh et al., 2000; Kirkova et al., 2012; Kirkova et al., 2010). However, another study, using the NEQ in a mixed cancer population, did not find significant differences between younger and older patients, except for needs regarding patients' intimacy and support (Romito et al., 2011).

Additionally, in the present population, more than half of the breast and lung ACPs reported more than eight needs, while lung ACPs reported significantly higher unmet supportive care needs in assistance and treatment domain. Previous studies have shown a large number of unmet needs in lung ACPs with more prevalent those of the psychological/emotional, physical and communicational domains (Ugalde et al., 2012; Li & Girgis, 2006). Our findings for high assistance and treatment needs including better control of symptoms, more help for eating, dressing, better attention from nurses and others may be due to poor life expectancy and many serious problems related to lung cancer as compared to other neoplastic diseases (Li & Girgis, 2006).

Four of the five most prevalent unmet needs reported in this study were informational, related to diagnosis, prognosis, results of examinations and type of treatment. Similar high informational needs were found in patients with different types of cancer and disease stages using the same questionnaire (Romito et al., 2011; Tamburini et al., 2003; Tamburini et al., 2000). Furthermore, high unmet needs in the communicational/informational, physical and psychological domains have been reported by other authors using different questionnaires (Edib et al., 2016; Kritsotakis, Koutis, Kotsori, Alexopoulos, & Philalithis, 2010; Rainbird et al., 2009). Several studies have been carried out investigating the type, sources, appropriate time and level of information provided and its influence on the patients' quality of life (Marcusen, 2010; Wong et al., 2002). Patients were found to seek more information about symptom management, their prognosis, quality of life, clinical trials and home palliative care resources (Danesh, Belkora, Volz, & Rugo, 2014; Wong et al., 2002). Unfortunately, in everyday practice there are many factors obstructing satisfactory information (Marcusen, 2010; Bahti, 2010). For example, many patients believe that some problems are inevitable with cancer and don't ask, while others still feel that the information is unclear by its nature (Bahti, 2010; Tamburini et al., 2003). Additionally, many times there are requests from family members to conceal information about prognosis (Hancock et al., 2007). On the other hand some health professionals often do not have enough communication skills or they don't understand the patient's unmet needs. Hence, they focus only on the management of symptoms expressed by the patients, while they work under pressure due to time restrictions that exist in demanding clinical settings (Marcusen, 2010; Rainbird et al., 2009; Hancock et al., 2007; Tamburini et al., 2000). Filling the gaps of informational needs helps the patient to understand the disease, diminish uncertainty, have realistic expectations, decrease anxiety and better

participate in the disease's management (Husson, Mols, & van de Poll-Franse, 2011; Hurny, 2002).

In the present study ACPs had expressed the desire to speak with people who have had the same experience. This may be an alternative way to find sources of information and to satisfy their unmet informational needs. Additionally, interaction with patients having the same experience helps them to acquire knowledge about successful management of the difficulties and the fears they may be experiencing, receive support, encouragement and guidance, and therefore, to better cope with their disease (Rini et al., 2007).

The present findings have shown an overall low need for attention from nurses, respect of intimacy and for need for help with every day activities. This is probably due to two reasons. The study was conducted in a well-established oncology department, where, although nurses work excessively under intense conditions, they are well trained and experienced to manage situations patients consider as nursing tasks. Additionally, family members are always present, supporting the health care professionals, as part of the caring team.

It is of note that most of present patients have expressed an overall satisfaction despite a number of unmet needs. The less satisfied patients expressed communicative, assistance and treatment and structure needs. Satisfaction is of utmost importance, since it can be associated with better outcome (Bredart et al., 2013). Hence, it is important to identify specific unmet needs among unsatisfied ACPs and examine how they influence satisfaction.

The present study has some limitations. Firstly, the data were collected only from the island of Crete and, therefore, generalization should be made with caution. Nevertheless, the study had been conducted in the only major oncology center, serving patients from different areas of the island with diverse socioeconomic backgrounds. Secondly, the Greek version of NEQ was used for first time in hospitalized ACPs with solid tumors. Thirdly, due to its design, the NEQ doesn't cover the full spectrum of needs and the burden that may have on ACPs. However, such questionnaires are used more as screening tools to reveal needs and find subgroups of patients for more in detail interventions. Finally, a relative limitation is that the study was carried out a few years ago. However, improvements in treatment and increased survival over the last years, did not significantly change nursing care and the appearance and frequency of symptoms in patients with advanced cancer.

5. Conclusions

The Greek version of NEQ displayed adequate psychometric properties and was easily handled by both the health professionals and patients. This study reported a high prevalence of informational unmet needs with younger and female patients reporting more needs than their older and male counterparts. Most patients expressed overall satisfaction despite a number of unmet needs. Thus, the NEQ is a promising, useful tool in everyday clinical practice for obtaining information for supportive care needs. Integrated and effective patient-centered care should recognize and address each and every patient's needs; this will help to reduce the burden of symptoms, improve supportive interventions and maintain high quality of care.

Competing Interests Statement

The authors declare that there is no conflict of interests regarding the publication of this paper.

References

Abernethy, A. P., Wheeler, J. L., & Currow, D. C. (2010). Utility and use of palliative care screening tools in routine oncology practice. *Cancer J, 16*(5), 444-460. http://dx.doi.org/10.1097/PPO.0b013e3181f45df0

Alexopoulos, E. C., Koutsogiannou, P., Moratis, E., Mestousi, A., & Jelastopulu, E. (2011). Pain in cancer patients: the Greek experience. *Eur J Oncol Nurs, 15*(5), 442-446. http://dx.doi.org/10.1016/j.ejon.2010.10.008

Annunziata, M. A., Muzzatti, B., Bidoli, E., & Veronesi, A. (2012). Emotional distress and needs in Italian cancer patients: prevalence and associations with socio-demographic and clinical factors. *Tumori, 98*(1), 119-125. http://dx.doi.org/10.1700/1053.11510

Annunziata, M. A., Muzzatti, B., & Bidoli, E. (2010). Psychological distress and needs of cancer patients: A prospective comparison between the diagnostic and the therapeutic phase. *Support Care Cancer, 19*(2), 291-295. http://dx.doi.org/10.1007/s00520-010-0818-9

Bahti, T. (2010). Coping issues among people living with advanced cancer. *Semin Oncol Nurs, 26*(3), 175-182. http://dx.doi.org/10.1016/j.soncn.2010.05.001

Brédart, A., Kop, J. L., Griesser, A. C., Fiszer, C., Zaman, K., Panes-Ruedin, B., … Dolbeault, S. (2013). Assessment of needs, health-related quality of life, and satisfaction with care in breast cancer patients to better target supportive care. *Ann Oncol, 24*(8), 2151-2158. http://dx.doi.org/10.1093/annonc/mdt128

Bužgová, R., Hajnová, E., Sikorová, L., & Jarošová, D. (2014). Association between unmet needs and quality of

life in hospitalised cancer patients no longer receiving anti-cancer treatment. *Eur J Cancer Care*, *23*(5), 685-694. http://dx.doi.org/ 10.1111/ecc.12181

Carey, M., Lambert, S., Smits, R., Paul, C., Sanson-Fisher, R., & Clinton-McHarg, T. (2012). The unfulfilled promise: a systematic review of interventions to reduce the unmet supportive care needs of cancer patients. *Support Care Cancer, 20*(2), 207-219. http://dx.doi.org/10.1007/s00520-011-1327-1

Carlson, L. E., Waller, A., & Mitchell, A. J. (2012). Screening for distress and unmet needs in patients with cancer: review and recommendations. *J Clin Oncol, 30*(11), 1160-1177. http://dx.doi.org/10.1200/JCO.2011.39.5509

Danesh, M., Belkora, J., Volz, S., & Rugo, H. S. (2014). Informational needs of patients with metastatic breast cancer: what questions do they ask, and are physicians answering them? *J Cancer Educ, 29*(1), 175-180. http://dx.doi.org/ 10.1007/s13187-013-0566-x

Edib, Z., Kumarasamy, V., Binti Abdullah, N., Rizal, A. M., & Al-Dubai, S. A. (2016). Most prevalent unmet supportive care needs and quality of life of breast cancer patients in a tertiary hospital in Malaysia. *Health Qual Life Outcomes,* 14:26. http://dx.doi.org/10.1186/s12955-016-0428-4

Efstathiou, N., Ameen, J., & Coll, A. M. (2008). A Delphi study to identify healthcare users' priorities for cancer care in Greece. *Eur J Oncol Nurs, 12*(4), 362-371. http://dx.doi.org/10.1016/j.ejon.2008.04.010

Elkin, E. B., Kim, S. H., Casper, E. S., Kissane, D. W., & Schrag, D. (2007). Desire for information and involvement in treatment decisions: elderly cancer patients' preferences and their physicians' perceptions. *J Clin Oncol, 25*(33), 5275-5280. http://dx.doi.org/10.1200/JCO.2007.11.1922

Glare, P. A. (2013). Early implementation of palliative care can improve patient outcomes. *J Natl Compr Canc Netw, 11* Suppl 1, S3-9.

Govina, O., Kotronoulas, G., Mystakidou, K., Katsaragakis, S., Vlachou, E., & Patiraki, E. (2015). Effects of patient and personal demographic, clinical and psychosocial characteristics on the burden of family members caring for patients with advanced cancer in Greece. *Eur J Oncol Nurs*, *19*(1), 81-88. http://dx.doi.org/10.1016/j.ejon.2014.06.009

Hancock, K., Clayton, J. M, Parker, S. M., Wal der, S., Butow, P. N., Carrick, S., … Tattersall, M. H. (2007). Truth-telling in discussing prognosis in advanced life-limiting illnesses: A systematic review. *Palliat Med, 21*(6), 507-517. http://dx.doi.org/ 10.1177/0269216307080823

Harrison, J. D., Young, J. M., Price, M. A., Butow, P. N., & Solomon, M. J. (2009). What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer, 17*(8), 1117-1128. http://dx.doi.org/10.1007/s00520-009-0615-5

Hürny C. (2002). Do patients with advanced cancer get appropriate information? *Support Care Cancer, 10*(5), 383-384. http://dx.doi.org/10.1007/s00520-002-0379-7

Husson, O., Mols F., & van de Poll-Franse L. V. (2011). The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol, 22*(4), 761-772. http://dx.doi.org/10.1093/annonc/mdq413

Kirkova, J., Rybicki L., Walsh, D., Aktas, A. (2012). Symptom prevalence in advanced cancer: age, gender, and performance status interactions. *Am J Hosp Palliat Care, 29*(2), 139-145. http://dx.doi.org/10.1177/1049909111410965

Kirkova, J., Walsh, D., Rybicki, L., Davis. M. P., Aktas, A., Tao Jin, Homsi, J. (2010). Symptom severity and distress in advanced cancer. *Palliat Med, 24*(3), 330-339. http://dx.doi.org/10.1177/0269216309356380

Kritsotakis, G., Koutis, A. D, Kotsori, A., Alexopoulos, C. G., & Philalithis, A. E. (2010). Measuring patient satisfaction in oncology units: interview-based psychometric validation of the 'Comprehensive Assessment of Satisfaction with Care' in Greece. *Eur J Cancer Care, 19*(1), 45-52. http://dx.doi.org/10.1111/j.1365-2354.2007.00910.x

Li, J., & Girgis, A. (2006). Supportive care needs: Are patients with lung cancer a neglected population? *Psychooncology, 15*(6), 509-516. http://dx.doi.org/10.1002/pon.983

Linardakis, M., Papadaki, A., Smpokos, E., Micheli, K., Vozikaki, M., & Philalithis, A. (2015). Relationship of behavioral risk factors for chronic diseases and preventive health services utilization among adults, aged 50+, from eleven European countries. *J Public Health,* 23:257. http://dx.doi.org/10.1007/s10389-015-0683-6

Marcusen, C. (2010). Information and communication needs of individuals living with advanced cancer. *Semin*

Oncol Nurs, 26(3), 151-156. http://dx.doi.org/10.1016/j.soncn.2010.05.006

Medical Outcomes Trust. **(**1997). Trust introduces new translation criteria. *Trust Bulletin,5*, 1-4.

Moghaddam, N., Coxon, H., Nabarro, S., Hardy, B., & Cox, K. (2016). Unmet care needs in people living with advanced cancer: a systematic review. *Support Care Cancer, 24*(8), 3609-3622. http://dx.doi.org/10.1007/s00520-016-3221-3

Mystakidou, K., Tsilika, E., Parpa, E., Katsouda, E., Galanos, A., & Vlahos, L. (2006). Psychological distress of patients with advanced cancer: influence and contribution of pain severity and pain interference. *Cancer Nurs, 29*(5), 400-405.

Pearce, M. J., Coan, A. D., Herndon, J. E. 2nd, Koenig, H. G., & Abernethy, A. P. (2012). Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. *Support Care Cancer, 20*(10), 2269-2276. http://dx.doi.org/10.1007/s00520-011-1335-1

Peppercorn, J. M., Smith, T. J., Helft, P. R., Debono, D. J., Berry, S. R., Wollins, D.S., … Schnipper, L. E. (2011). American society of clinical oncology statement: toward individualized care for patients with advanced cancer. *J Clin Oncol, 29*(6), 755-760. http://dx.doi.org/10.1200/JCO.2010.33.1744

Rainbird, K., Perkins, J., Sanson-Fisher, R., Rolfe, I., & Anseline, P. (2009). The needs of patients with advanced, incurable cancer. *Br J Cancer, 101*(5), 759-764. http://dx.doi.org/ 10.1038/sj.bjc.6605235

Richardson, A., Medina, J., Brown, V., & Sitzia, J. (2007). Patients' needs assessment in cancer care: a review of assessment tools. *Support Care Cancer, 15*(10), 1125-1144. http://dx.doi.org/10.1007/s00520-006-0205-8

Rini, C., Lawsin, C., Austin, J., DuHamel, K., Markarian, Y., Burkhalter, J., … Redd, W. (2007). Peer mentoring and survivors' stories for cancer patients: positive effects and some cautionary notes. *J Clin Oncol, 25*(1), 163-166. http://dx.doi.org/ 10.1200/JCO.2006.08.8567

Romito, F., Corvasce C., Montanaro R., & Mattioli, V. (2011). Do elderly cancer patients have different care needs compared with younger ones? *Tumori, 97*(3), 374-379. http://dx.doi.org/ 10.1700/912.10037.

Schenker, Y., Park, S. Y., Maciasz, R., & Arnold, R. M. (2014). Do patients with advanced cancer and unmet palliative care needs have an interest in receiving palliative care services? *J Palliat Med, 17*(6), 667-672. http://dx.doi.org/10.1089/jpm.2013.0537

Tamburini, M., Gangeri, L., Brunelli, C., Beltrami, E., Boeri, P., Borreani, C., … Trimigno, P. (2000). Assessment of hospitalised cancer patients' needs by the Needs Evaluation Questionnaire. *Ann Oncol, 11*(1), 31-37.

Tamburini, M., Gangeri, L., Brunelli, C., Boeri, P., Borreani, C., Bosisio, M., … Trimigno, P. (2003). Cancer patients' needs during hospitalisation: a quantitative and qualitative study. *BMC Cancer,* 3:12.

Uchida, M., Akechi, T., Okuyama, T., Sagawa, R., Nakaguchi, T., Endo, C., … Furukawa, T. A. (2011). Patients' supportive care needs and psychological distress in advanced breast cancer patients in Japan. *Jpn J Clin Oncol, 41*(4), 530-536. http://dx.doi.org/10.1093/jjco/hyq230

Ugalde, A., Aranda, S., Krishnasamy, M., Ball, D., & Schofield, P. (2012). Unmet needs and distress in people with inoperable lung cancer at the commencement of treatment. *Support Care Cancer, 20*(2), 419-423. http://dx.doi.org/10.1007/s00520-011-1296-4

Walsh, D., Donnelly, S., & Rybicki, L. (2000). The symptoms of advanced cancer: relationship to age, gender, and performance status in 1 000 patients. *Support Care Cancer, 8*(3), 175-179.

Wessels, H., de Graeff, A., Wynia, K., de Heus, M., Kruitwagen, C. L., Woltjer, G. T, … Voest, E. E. (2010). Gender-related needs and preferences in cancer care indicate the need for an individualized approach to cancer patients. *Oncologist, 15*(6), 648-655. http://dx.doi.org/10.1634/theoncologist.2009-0337

Wong, R. K., Franssen, E., Szumacher, E., Connolly, R., Evans, M., Page B., … Danjoux, C. (2002). What do patients living with advanced cancer and their carers want to know? - a needs assessment. *Support Care Cancer, 10*(5), 408-415. http://dx.doi.org/10.1007/s00520-002-0354-3

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