



Patients and caregivers' unmet information needs in the field of patient education: results from an Italian multicenter exploratory survey

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Abstract

Patient education and empowerment (PEE) is aimed at improving competence of patients during their clinical path and enabling healthcare providers with specific communication strategies. We investigated the interest of Italian Cancer Research & Care Centers (CRCI) users (patients and caregivers) in being involved in PEE activities. An anonymous questionnaire addressed to users was distributed between June 2013 and February 2014. The questionnaire gathered information on the following: health-related topics; 13 different PEE initiatives/modalities of learning already active at CRCI; personal demographic data; the willingness to be more involved in the organization of health services provided and in which context; and five preferred info-educational activities. Frequency distribution and chi-square analysis were computed. Statistical significance (p value) was set at <0.05 . A total of 875 (29%) users responded to the 3000 distributed questionnaires. The first three priorities of interest were “early diagnosis” (18%), “prevention” (17%), and “diagnosis explanation” (13%). The first three priorities on informational activity were as follows: “classes on cancer-related topics with healthcare professionals” (28%); “cancer information service” (22%); “drug information point” (7%). Forty-nine percent of the respondents stated that they would like to be involved in the organization of PEE activities, particularly caregivers and users older than 55 years of age. The preferred educational activities were “classes on cancer-related topics with healthcare professionals” and “cancer information service” on a face-to-face modality. Patients were more interested than caregivers in “prevention.” The extension of PEE programs to all CRCI users into routine care will be the next step of the present research.

Keywords Cancer care · Patient education · Patient empowerment · Unmet needs · Observational cross-sectional study · Italy · Questionnaires

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Background

Over the past five decades, patient education has moved towards a more proactive, person-centered and bidirectional approach [1–6]. Today patient education programs have the dual goal of improving competence of patients as well as providing healthcare providers with specific communication strategies aimed at understanding patients' needs and empowering them to take on a leading role in their own clinical path, while striving to bridge the gap between doctors and patients [7, 8], i.e., Patient Education & Empowerment (PEE) [9–12]. Meeting this objective is quite a challenge to healthcare organizations, as it requires planned efforts to set up appropriate tools and resources to meet patients' actual needs [7, 11, 13–15].

The literature on the importance of assessing patients' needs is quite substantial and crucial in addressing healthcare resources [16]. It is well understood that unmet needs have a negative impact on cancer patient and survivors' quality of life [17], satisfaction with care [18], perceived symptoms [19], rehabilitation [20], follow-up [21], and access to palliative care [22]. The vast majority of previous studies were carried out by health professionals, i.e., psychologists, medical doctors, or nurses. These studies focused on the areas of symptom burden (anxiety, pain, fear of recurrence, etc.), functioning (cognitive, sexual, social, etc.), health behavior (diet, physical exercise, etc.), financial strain (insurance, costs, income loss, etc.) while others focused on healthcare seeking behaviors (healthcare competence, health information, etc.) [23] or addressed only a particular population, for instance, elderly patients [24, 25].

A multidisciplinary approach researching cancer patients' unmet needs along with an overall assessment of caregivers' unmet needs in relation to PEE activities is, thus, still missing, in Italy, and still limited in other countries (i.e., Belgium or France [26]).

In order to achieve a better planning of an institutional policy of PEE, it is necessary to investigate the overall potential interest of Italian Cancer Research & Care Centers (CRCI) users (patients and caregivers together) in being involved in PEE activities first. We thus surveyed which approach and timing users prefer to be informed, and finally we conducted a general investigation on the potential topics of main interest of patients and caregivers.

This survey is the second step within the first aim of a 2013–2015 multicenter research project, aimed at actualizing PEE in healthcare Institutions [15].

Material and methods

The study design followed an observational cross-sectional study criteria. We investigated the patients/caregivers' information needs and their preferred information modalities in

five Italian CRCI: CRO Aviano, IOV Padua, INT Milan, IRST Meldola, ASMN Reggio Emilia. These Institutes are partners in the “Extending Comprehensive Cancer Centers' Expertise in PEE” research project. Each Institute undergoes periodic external quality controls aiming at accreditation to achieve excellence. Furthermore, each one of the CRCI underwent the quality accreditation process of the Organization of European Cancer Institutes (OECI). One of the foundations of the OECI model for assessing and benchmarking care and research is specifically focused on patient experience and involvement [27, 28]. The ethical committees of each one of the CRCI approved the survey.

A purpose-designed, anonymous, questionnaire addressed to users (patients and caregivers) was distributed between June 2013 and February 2014. The questionnaire was available in specific patient areas of the five participating centers, including reception desks, examination rooms, cancer information points, admission offices, and patient libraries. Users who volunteered to participate returned the completed questionnaires to patient libraries or to specific survey boxes located throughout the participating hospitals. The collected information was anonymously computerized by a trained operator in each hospital into a centralized spreadsheet for data collection. The topics of the questionnaire were identified according to the following criteria: (a) the most requested topics by the healthcare users attending the CRO Patients Library (patients and their relatives above all) [28]; (b) the results from a multicenter national survey conducted in Italy, involving 3888 users attending the 17-information-facilities network, National Cancer Information Service in Italy [29]; (c) a list of “hot topics” emerging from the organizational meetings of the Institutions belonging to the Italian Cancer Patient Education Group [15].

The questionnaire consisted of five main sections: (i) the first section presented a list of 20 health-related topics, such as nutrition, clinical trials, cancer treatments, complementary and alternative medicines (CAM), informed consent, etc. The participants were asked to rank the five topics of highest interest by sorting them in order of importance from the first to the fifth; (ii) the second one consisted of a list of 13 different PEE initiatives or modalities of learning already active at the Italian CRCI, as emerged from our first survey [15], for instance, informative booklets, classes on cancer-related topics with healthcare professionals, drug or cancer information points, actual hand-on exercise classes, cooking classes, helplines, etc. An open-ended response option box was provided for both questions to write in responses; (iii) this section collected information on personal demographic data, i.e., sex, age (< 55; ≥ 55), type of user (patient; caregiver), and education level (low, primary plus secondary school; high, high school plus university); (iv) in the fourth and fifth sections, the respondents were asked whether they wanted to be more involved in the organization of the health services provided, and in which

context; (v) the participants were asked to select the top five preferred info-educational activities to learn about from the topics chosen in the previous question, including when (timing) during their patient journey they would like to receive them (third section).

Statistical analysis

Frequency distribution and chi-square analysis were computed by means of SPSS version 23. Statistical significance was set at <0.05 p value. The questionnaire is available online as supplementary material.

Results

A total of 3000 questionnaires were distributed. Respondents were 875 (29%) of whom, 62% were females, 51% were ≥ 55 years old, 70% were patients, and 67% had a high education level (Table 1).

Table 1 Sample distribution according to sex, age, type of user, education, institute, and sorted preferences ($n = 875$)

	<i>N</i>	%
Sex ^a		
Male	300	34
Female	542	62
Age (years) ^a		
Age < 55	395	45
Age ≥ 55	443	51
Type of user ^a		
Patient	612	70
Caregiver	204	23
Education ^a		
Low (elementary and secondary school)	258	29
High (high school and university)	582	67
Institute		
ASMN	9	1
CRO	194	22
INT	256	29
IOV	388	44
IRST	28	3
Sorted preferences		
Yes	735	84
No	140	16
Desire to be involved in the organization of healthcare system ^a		
Yes	342	39
No	352	40

^a The sum may not add up to the total because of missing values

Eighty-four percent of respondents (i.e., $N = 735$) ranked the five most interesting topics and educational activities in the prioritized questionnaire (Table 1). High educated versus less educated respondents accomplished mostly prioritized topics and activities ($p < 0.01$). The priorities of interest were “early diagnosis” (18%), followed by “prevention” (17%), “diagnosis explanation” (13%), “clinical trials” (10%), “nutrition for specific tumors” (7%), “nutrition” (6%), and “informed consent” (1%). “Prevention” was ranked first mainly by the patients ($p = 0.03$) (Table 2).

The priorities of informational activity were as follows: “classes on cancer-related topics with healthcare professionals” (28%); followed by “cancer information service” (22%); “drug information point” (7%); “informative booklets” (7%); “physical rehabilitation activities” (7%), “dedicated interactive websites” (6%), “physical activity” (5%); and “social media” (2%). “Cancer-related classes with healthcare professionals” was ranked first mainly by < 55 -year-old respondents ($p = 0.01$) and “dedicated, interactive websites” by men ($p = 0.02$) while “physical activity” by less educated people ($p = 0.02$), and “social media” by patients ($p = 0.02$) (Table 3).

Information on “clinical trials” seemed important at the “beginning of therapy” ($p = 0.03$) and “prevention” or “nutrition for specific tumor” were important at any step of their clinical path ($p < 0.01$) (Table 4).

Out of the 735 respondents who ranked the topics, 49% stated that they would like to be involved in the organization of PEE activities. In particular, 62% were women, 56% were ≥ 55 years old, 66% were patients, and 71% had a high education level. Caregivers were more interested than patients in “health services reorganization” ($p = 0.04$), in “patient education activities” ($p < 0.01$), in “volunteering” ($p < 0.01$), and in “welcome services” ($p = 0.01$). People older than 55 years were more interested in “patient education activities” ($p = 0.03$) and in “volunteering” ($p = 0.04$). Men were more interested in being involved in “informational activities” ($p = 0.02$) (Supplementary Table 5, online materials). Among the respondents, the non-prioritized topics were “nutrition” (90%), followed by “clinical trials” (88%), “conventional treatments” (80%), “CAM” (74%), “radiotherapy” (65%), and “organization of health services” (52%). “Organization of health services” was mostly chosen by people ≥ 55 years old ($p = 0.03$) (Supplementary Table 5, online materials).

The preferred informational activities were “physical activity” (69%), followed by “arts & crafts labs” (68%); “Gym rehabilitation activities” (57%), and “cooking classes” (51%). Women chose more often than men “cooking classes” ($p = 0.03$) and “Cancer Information Point” ($p < 0.01$) (Supplementary Table 6, online materials). Three hundred forty-two (49%) respondents, out of 694, stated that they would like to be more involved in the organization of PEE activities (Table 1). They were mostly women (62%), patients (66%), and had a higher education (71%). More in detail,

Table 2 Frequency of requested information by topics when the first preference is specified (N = 735), according to sex, age, type of users, and education

Information topics	Ranking		Sex ^a		Age (years) ^a		Type of user ^a		Education ^a				
	N	%	Men N = 250 %	Women N = 462 %	p value	< 55 N = 324 %	≥ 55 N = 385 %	Patient N = 511 %	Caregiver N = 179 %	p value	Low N = 205 %	High N = 504 %	p value
Early diagnosis	129	18	18	17	0.11	20	17	17	17	0.91	32	29	0.31
Prevention	125	17	17	17	0.72	22	14	18	15	0.21	29	32	0.45
Diagnosis explanation	99	13	14	14	0.41	17	12	14	14	0.73	38	40	0.46
Clinical trials	75	10	13	9	0.12	13	9	9	13	0.93	17	19	0.84
Nutrition for specific tumors	52	7	6	8	0.94	11	4	8	5	0.08	21	31	0.32
Nutrition	47	6	5	7	0.12	8	5	6	8	0.87	12	11	0.42
Chemotherapy	33	4	5	4	0.83	6	4	5	4	0.50	25	22	0.72
Nutrition and therapies	25	3	2	4	0.27	5	3	4	3	0.69	19	26	0.88
Complementary therapies	24	3	4	3	0.86	3	4	4	3	0.13	14	20	0.76
Conventional treatments	17	2	2	2	0.66	2	2	2	2	0.53	14	13	0.15
Radiotherapy	17	2	3	2	0.13	1	4	3	1	0.02	13	12	0.35
Post-surgery home care	16	2	1	3	0.33	3	2	2	2	0.79	19	15	0.93
Side effects	15	2	2	2	0.73	2	2	3	1	0.63	34	37	0.29
Patients' rights	14	2	2	2	0.82	2	2	2	2	0.88	24	17	0.67
Organization of health services	13	2	1	2	0.61	2	2	2	2	0.96	13	9	0.57
Sexuality and cancer	8	1	1	1	0.99	2	1	1	2	0.33	9	11	0.10
Palliative care	6	1	1	1	0.52	1	1	0	2	0.92	9	10	0.59
Informed consent	6	1	0	1	0.54	2	0	0	2	0.03	10	5	0.51
Leisure activities for patients	6	1	1	1	0.84	1	1	1	1	0.58	2	6	0.17
Other	4	1	0	1	0.31	1	1	1	1	0.73	1	1	0.91
Drugs	3	0	0	0	0.85	0	1	1	0	0.04	14	14	0.87

^aThe sum may not add up to the total because of missing values

Table 3 Frequency of requested informational activities by topics when the first preference is specified (N = 735), according to sex, age, type of users, and education

Informational activities	Ranking		Sex ^a		Age (years) ^a		Type of user ^a		Education ^a		p value
	N	%	Men	Women	< 55	≥ 55	Patient	Caregiver	Low	High	
			N = 250	N = 462	N = 324	N = 385	N = 511	N = 179	N = 205	N = 504	
Cancer-related classes with health professionals	202	28	25	29	39	18	28	28	26	29	0.80
Cancer information point	159	22	21	22	23	21	20	28	26	21	0.06
Drug information point	51	7	9	6	7	8	7	6	8	7	0.59
Informative booklets	53	7	6	8	8	6	7	6	4	8	0.66
Gym rehabilitation activities	51	7	5	8	8	6	8	5	9	6	0.38
Dedicated, interactive websites	41	6	9	4	8	4	5	7	4	6	0.71
Physical activity	37	5	6	5	6	5	5	4	8	4	0.63
Helpline	18	2	1	3	3	2	3	3	1	3	0.78
Cooking classes	19	3	2	3	3	3	3	3	1	3	0.57
Arts & crafts labs	16	2	1	1	2	3	0	1	1	3	0.89
Meditation/yoga	18	2	2	3	3	2	3	0	1	3	0.05
Social media	11	2	2	1	3	1	2	0	1	2	0.02
Make-up labs	0	0	0	0	0	0	0	0	0	0	
Other	5	1	1	0	1	1	1	1	0	1	0.76

^aThe sum may not add up to the total because of missing values

Table 4 First information topic ($N = 735$) chosen by timing: first visit, beginning of therapy, discharge, follow-up, and at any step of clinical path

	Ranking		First visit		Beginning of therapy		Discharge		Follow-up		At any step of clinical path	
	<i>N</i>	%	%	<i>p</i> value	%	<i>p</i> value	%	<i>p</i> value	%	<i>p</i> value	%	<i>p</i> value
Diagnosis explanation	99	13	5	0.21	2	0.62	0	0.02	1	0.98	5	0.97
Early diagnosis	129	18	8	0.01	2	0.42	1	0.77	1	0.44	6	0.39
Prevention	125	17	5	0.39	1	<0.01	0	0.10	1	0.59	9	<0.01
Clinical trials	75	10	4	0.55	2	0.03	0	0.05	1	0.47	3	0.24
Side effects	15	2	0	0.28	1	0.05	1	<0.01	0	0.93	0	0.14
Nutrition for specific tumors	52	7	1	<0.01	1	0.71	1	0.22	0	0.48	4	<0.01
Complementary therapies	24	3	1	0.69	0	0.12	0	0.05	0	0.68	2	0.23
Nutrition	47	6	1	0.15	1	0.59	0	0.13	0	0.94	3	0.21
Chemotherapy	33	4	2	0.12	1	0.06	0	0.70	0	0.45	1	0.19
Nutrition and therapies	25	3	1	0.33	1	0.02	0	0.36	0	0.19	1	0.82
Conventional treatments	17	2	1	0.83	1	0.11	0	0.75	1	<0.01	0	0.08
Radiotherapy	17	2	0	0.18	1	0.36	0	0.13	0	0.29	0	0.08
Patients' rights	14	2	0	0.36	0	0.90	0	0.61	0	0.87	1	0.85
Post-surgery home care	16	2	1	0.50	0	0.08	1	<0.01	0	0.30	1	0.27
Organization of health services	13	2	1	0.31	0	0.12	0	0.44	0	0.81	0	0.26
Drugs	3	0	0	0.01	0	0.46	0	0.71	0	0.66	0	0.17
Sexuality and cancer	8	1	1	0.30	0	0.46	0	0.54	0	0.47	0	0.97
Palliative care	6	1	0	0.37	0	0.29	0	0.60	0	0.28	0	0.28
Informed consent	6	1	0	0.09	0	0.94	0	0.60	0	0.28	0	0.28
Leisure activities for in-patients	6	1	0	0.40	0	0.94	0	0.60	0	0.28	0	0.55
Other	4	1	0	0.47	0	0.39	0	0.67	0	0.11	0	0.59

caregivers better than patients were interested in the reorganization of some services provided such as day hospital, reception/front desk, hospital admission, etc. [Supplementary Table 7, online materials].

Discussion

This survey investigated the potential interest of patients and caregivers in being involved in the PEE activities, between June 2013 and February 2014, in five Italian CRCI. The most interesting result emerging from our study is a meaningful difference between patients and caregivers older than 55 years in being involved in the organization of “Patient education activities.” Approximately half of the respondents (49%) stated that they would like to be involved in the organization of PEE activities.

Forty-nine percent of respondents is not a discouraging result as the topic of patient preferences about patient involvement is still under investigation [30, 31]. For instance, as reported by Arora and McHorney [32], patients' preferences about participation in their own decision-making can be low while, in agreement with Malfait and collaborators [33], participation rate in investigating PEE can be quite similar to our study results.

Concerning the educational activities chosen by our respondents in relation to the first-ranked topic, a large preference emerged for a “face-to-face modality,” “classes on cancer-related topics with healthcare professionals,” and “cancer information service” [34, 35]. These results are in agreement with the conclusions of a study by Fleisher and colleagues [36] that “multiple communication approaches should be considered to support patient preferences.”

The choice of “clinical trials” may be an indicator of an increasing awareness of cancer patients attending Italian CRCI. However, this kind of interest is controversial in literature. A higher percentage of interest about “clinical trials” was observed specifically in patients with advanced breast cancer during breast oncology consultations and during visits with decision support services [37]. Nonetheless, users reported a low interest in the topic of informed consent. Conversely, a higher percentage of interest and satisfaction with informed consent emerged when this tool was properly employed [38]. Patients were more interested than caregivers in “prevention” ($p = 0.03$), which is likely associated with the increasing survival rates or with the cultural shift from cancer patient to cancer survivor [39].

The World Health Organization has underlined the necessity of encouraging an active and participatory role of patients in order to enhance their well-being, to improve

the efficiency of healthcare systems [40], and to increase shared decision-making by means of a bidirectional education approach [14, 41].

Finally, we observed that in 16% of the questionnaires, the respondents did not prioritize their choices, perhaps because they did not understand or accept the task of setting out their info-educational needs according to a priority. This could be interpreted as an indicator of low literacy. Nonetheless, this result needs further investigation.

Limitations

This study has several limitations. Users attending the five CRCI voluntarily and freely filled out the questionnaire. Although a self-selected sample could be a limit (self-selection bias) of the study, it is also a strong aspect to be considered, as there was no pressure or influence on the respondents to participate. Even so, many missing data were due to this freedom and lack of support, and the non-prioritized sub-sample responses may be a consequence. Furthermore, the patient education topic list and educational activities were not open-ended, but pre-selected on the basis of our previous survey [15]; thus, the respondents' choice may have been influenced by our previous PEE programs carried out in the participating CRCIs. We conducted a CRCI stratified analysis that produced non-conclusive and heterogeneous results across CRCI. Due to the self-selection of users in filling out the questionnaire, this survey is representative only for the North/Centre of Italy; consequently, the comparison of our results with similar studies cannot be carried out.

Conclusions

Nearly half of respondents in the present survey—both cancer patients and caregivers—reported a willingness of being involved in the organization of patient education activities and reorganization of some services, and a preference of being informed with a face-to-face modality. These results are very challenging. The next step of this research will be to integrate PEE programs into routine care, possibly involving the vast majority of patients and caregivers.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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