# Complementary needs behind complementary therapies in cancer patients

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#### **Abstract**

Objective: Although many studies indicate that the use of complementary and alternative medicine by cancer patients is common and widespread, few studies have focused on unmet needs of patients using complementary therapies (CTs). The aim of the present study was to evaluate, through a quantitative approach, possible associations between the use of CTs and the presence of specific unmet needs in cancer patients.

*Methods*: In six Italian oncology departments, 783 patients were interviewed about CTs use and completed the Needs Evaluation Questionnaire. Patients included in the study had different primary tumor sites and were in different phases of the disease and care process.

Results: At the time of the survey, 38.3% of patients were using one or more types of CTs. According to Needs Evaluation Questionnaire, the use of CTs was associated (p < .05) with the need to be more involved in therapeutic choices (40% vs. 31.7%), the need to have a better dialogue with clinicians (44.4% vs. 37.2%), and the need to have more economic-insurance information in relation to their illness (46.1% vs. 36.4%). Statistical significance was confirmed with multivariable analysis for the last two items, whereas three more needs were associated with the use of CTs after adjustment: to receive more explanation on treatments (46.8% vs. 41.0%), to receive more comprehensible information (38% vs. 31.9%), and to receive more attention from nurses (16% vs. 12.1%).

Conclusions: Our study shows interesting differences regarding perceived needs between cancer patients who use and who do not use CTs. Unmet needs that are more expressed in CTs users should be known and, when possible, could be taken into account to improve both psychosocial interventions in the context of conventional care process and the quality of the relationship between patient and medical and nursing staff.

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Received: 18 July 2014 Revised: 14 January 2015 Accepted: 20 January 2015

### Introduction

'Complementary/alternative medicine' (CAM) includes any medical system, practice, or product that is not thought of as standard care. The use of CAM by cancer patients is common and widespread [1,2]. A large number of studies have shown that only a small proportion of cancer patients use CAM with curative intent; most patients use CAM to improve general health conditions, to support medical treatments, or to treat physical symptoms [3–5]. Moreover, CAM therapies are frequently used along with mainstream cancer treatments and therefore should be considered 'complementary therapies' (CTs). The most commonly used CTs include mind-body approaches (e.g., meditation, relaxation, hypnotherapy, and visualization), botanical preparation, homeopathy, acupuncture, dietary approaches and food supplements, Chinese and other traditional medications, and spiritual healing.

Recently, we carried out a study in Italian Oncology Units of the Public Health Care System of Tuscany to evaluate the use of CTs and to deepen our knowledge of the unmet needs of patients. Overall prevalence of CTs among Italian cancer patients was high and was in accordance with the European average, because 37.9% of the patients at the time of measurement were using one or more types of CTs. The most commonly used CTs were diets and dietary supplements (27.5%), herbs (10.8%), homeopathy (6.4%), and mind-body therapies (5.5%). The Italian context was characterized by a high percentage of patients who informed their physicians about CT use (66.3%) and who experienced benefits (89.6%) [3]. The analysis of the present report is part of this larger study.

Several needs emerge in patients diagnosed with cancer; some of the most important refer to the possibility to be cured or to have lives prolonged, the control of

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Psycho-Oncology 1125

symptoms, along with information, moral, and spiritual support [6–8]. A significant proportion of these needs remain unmet. Data from literature suggest the importance of a needs assessment in the oncology clinical context because many patients and caregivers do not spontaneously communicate concerns to their clinicians, particularly psychosocial concerns; clinical interviews and specific questionnaires are therefore important instruments to assess unmet needs [7]. Several authors have argued that cancer patients and their families could seek out alternative and CTs at some point during their illness because the conventional health field does not fully understand and respond to their needs [5,6,9]. Paltiel et al. reported that the oncology patients believe that conventional therapy that did not meet their needs was a factor strongly associated with the use of CTs [9]. Despite these general considerations, few studies have focused on the description of which specific unmet needs are more present in patients using CTs. A recent qualitative study on 34 men with cancer who were using CAM therapies has shown that their utilization was often alongside that of conventional therapies. The use of CAM was the expression of a desire for active participation in their own treatment, a desire for good communication, a desire to more effective relief from the symptoms and side effects of treatment, and a desire to be perceived as a 'wholeperson' with physical, psychosocial, and spiritual concerns [10]. We think that deepening the knowledge of the unmet needs that could encourage patients to turn to CTs use would be very useful both to be able to target more efficiently the training of medical and nursing staff and to increase the presence, within the team of Oncology Units, of specialists with specific skills in psychosocial and spiritual field.

The aim of the present study was to evaluate, in cancer patients, through a quantitative approach, possible correlation between the use of CTs and the presence of specific unmet needs assessed with the 'Needs Evaluation Questionnaire'.

# Patients and methods

# 2.1 Study sample

The present study is part of a wider survey on unmet needs and complementary therapy use by Italian cancer patients [3]. It involved patients from six different oncology medical units in Tuscany, Italy: (a) *Centro Riabilitazione Oncologica* of the *Istituto per lo Studio e la Prevenzione Oncologica*, *Firenze*; (b) *Oncologia Medica Aziendale AUSL 10 Firenze*; (c) *Oncologia Medica AUSL 4 Prato*; (d) *Oncologia Medica AUSL 1 Massa Carrara*; (e) *Oncologia Medica*, *Azienda Ospedaliero Universitaria Careggi*, *Firenze*; and (f) *SOD Oncologia Medica* 2, *DAI Oncologia*, *Azienda Ospedaliero Universitaria di Careggi*, *Firenze*.

During the period of study, participation was proposed to all patients consecutively visiting outpatients' clinics or admitted to oncology wards, regardless of site or stage of the tumor. The study was proposed by the psychooncologist of the unit to inpatients 2 days after admission and to outpatients excluding the first day hospital treatment or the first ambulatory visit.

Particular care was exercised to avoid coercion to join the study emphasizing to patients that participation was totally free and voluntary and that nonadherence did not alter the care delivered by the staff of the ward.

Exclusion criteria were as follows: age younger than 18 years or older than 90 years, cognitive impairment, comorbid psychotic illness, learning disabilities, and severe symptoms due to illness or side effects of therapy that precluded, because of physical limitation, the ability to fill in questionnaires autonomously.

The study received the approval of the Local Ethics Committees of Careggi Hospital, of AUSL 10 in Florence, of *AUSL* 4 in Prato and of *AUSL* 1 Massa Carrara. Patients were asked to give written informed consent and received an informative sheet on the study.

## 2.2 Data collection

A semi-structured interview was developed for Italian participants by translating and adapting items from similar questionnaires used in recent studies [11,12]. Each patient was initially interviewed by the psycho-oncologist. The interviewer asked about the use of CTs (i.e., reasons for present use, perceived benefits, sources of information, and physician/relative knowledge about the use of CTs, annual cost) [3]. Clinical data were provided by oncologists.

To evaluate unmet needs, the *Needs Evaluation Questionnaire* (*NEQ*) was employed. The NEQ is a self administered instrument with 23 dichotomous items, which can be used in both clinical practice and in research, assessing needs in five areas: informative needs, needs related to assistance/care, relational needs, needs for a psychoemotional support, and material needs [13–15].

# 2.3 Statistical analysis

The usual univariate descriptive statistics were performed. Differences between CTs users and nonusers were tested through a chi square test, as well as the association of use of CTs with each NEQ item. To take into consideration the 'intensity' of CT use, we summed up the number of different kinds of CTs used for each patient  $(0, 1, 2, \text{ and } \ge 3)$ . To take into consideration the factorial structure of NEQ, we computed a patient areaspecific score for each of the five areas of NEQ (total number of needs expressed divided by the total number of needs for that area). To adjust for potential confounding, we fitted logistic multivariable regression models

I 126 A. Bonacchi et al.

separately for each NEQ item, including all the variables associated with the use of CTs presented in Table 1; backward stepwise procedure with significance level for removal from the model = .05 was used. Similarly, the association between area-specific scores and the number of CTs used (included in the model as categorical variable) was tested through bivariate and multiple linear regression; the last one was fitted for each needs area separately, using a backward selection procedure of the covariates with significance level for removal from the model = .05 and needs score treated as

lockterm. All analyses were conducted with the complete data available, considering missing at random any missing information. Analyses were performed using the statistical package STATA 12 (StataCorp. 2011. Stata Statistical Software: Release 12. College Station, TX: StataCorp LP).

#### Results

Nine hundred eighty patients were invited to participate in the research; 803 of them accepted were interviewed and

Table I. Basic demographic and clinical characteristics of patients included in the analysis (participants)

	Not using CTs		Using CTs		All			
	N	%	N	%	N	%	p-value	
	483		300		783			
Age (mean)							<.001	
18–49	62	12.9	59	19.7	121	15.5		
50–59	86	17.9	92	30.7	178	22.8		
60–69	170	35.4	77	25.7	247	31.7		
≥70	162	33.8	71	23.7	233	29.9		
Gender							<.001	
Female	277	57.7	232	77.3	509	65.3		
Male	203	42.3	68	22.7	271	34.7		
Marital status							.041	
Single	36	7.6	37	12.4	73	9.5		
Married	337	71.2	210	70.4	547	71.2		
Divorced	28	5.9	22	7.4	50	6.1		
Widowed	72	15.2	29	9.7	101	13.1		
Educational level							<.001	
Primary school	180	39.7	64	22.0	244	32.8		
Secondary school	101	22.3	66	22.7	167	22.4		
High school	121	26.7	100	34.4	221	29.7		
University	51	11.3	61	21.0	112	15.0		
Oncology care settings							<.001	
Ward	141	29.2	54	18.0	195	24.9		
Day hospital	130	26.9	63	21.0	193	24.6		
Ambulatory	110	22.8	69	23.0	179	22.9		
Rehabilitation unit	102	21.1	114	38.0	216	27.6		
Primary tumor site							.001	
Breast	163	35.7	153	53.7	316	42.6		
Lung	69	15.1	33	11.6	102	13.8		
Colon-rectum	58	12.7	27	9.5	85	11.5		
Pancreas	18	3.9	9	3.2	27	3.6		
Stomach	16	3.5	8	2.8	24	3.2		
Lymphoma	9	2.0	4	1.4	13	1.7		
Other	123	27.0	51	17.9	174	23.5		
Phase of the disease and care process							.017	
Diagnosis and treatments	199	46.9	96	36.0	295	42.7		
Follow up and/or rehabilitation	163	38.4	134	50.2	297	43.0		
Relapse/recurrence	24	5.7	16	6.0	40	5.8		
Progression of the disease and palliative care	38	9.0	21	7.9	59	8.5		
Treatment received								
Chemotherapy	307	68.8	204	72.1	511	70.1	.350	
Radiotherapy	143	32.1	128	45.4	271	37.3	<.001	
Months from diagnosis							.028	
0–6	130	32.5	56	21.7	186	28.3		
7–24	100	25.0	76	29.5	176	26.7		
25–60	81	20.2	62	24.0	143	21.7		
>60	89	22.2	64	24.8	153	23.2		

CTs, complementary therapies.

Psycho-Oncology 1127

filled in the proposed questionnaires. The percentage of patients who accepted the proposal to take part in the research ranged from 71.0% of Centro Riabilitazione Oncologica, Istituto per lo Studio e la Prevenzione Oncologica (rehabilitation unit) up to 95.4% of Oncologia Medica AUSL 4 Prato (oncology ward, day hospital, and ambulatory). The reasons for the refusal to participate in the study included mainly low interest in the topic of the study, engagement in diagnostic or therapeutic procedures, and engagement in activities that followed the outpatient ambulatory visits. The NEQ was filled in by 783 patients with less than seven missing items; these 783 patients constituted the sample used for the analyses described in the present report. Table 1 shows the distribution of clinical and sociodemographic characteristics in the sample, by CT use. At the time of the survey, 38.3% of patients included in our sample were using one or more types of CTs. Younger patients, female, single, those with higher education level, who received radiotherapy, actually in follow up/rehabilitation, and with larger distance form diagnosis had higher probability to be CTs users at the bivariate analyses.

The percentage of affirmative answers (i.e., the presence of unmet needs) to NEQ items varied according to different kinds of needs (Table 2). Lower percentages of positive answers were observed for needs related to assistance and care (items 10, 11, and 12) and needs for a psychosocial support (items 17 and 18), while higher percentages were observed for informative needs (items 1–8). This observation was in accordance with previous data resulting from NEQ use in clinical contexts [13,14].

We evaluated the percentage of NEQ affirmative answers distribution in patients using or not using CTs. Patients using CTs had a higher percentage of some unmet needs regarding information, dialogue with clinicians, and involvement in the therapeutic choices.

In particular, using  $\chi^2$ -test, we observed that three specific needs were associated (p < .05) with the use of CTs:

- 1. Need to be more involved in the rapeutic choices (item 5).
- 2. Need to have a better dialogue with clinicians (item 8).
- Need to have more economic-insurance information (tickets, invalidity, etc.) in relation to the illness (item 15).

After adjusting for variables present in Table 1, statistical significance was confirmed for the last two items: the need to have a better dialogue with clinicians (item 8) odds ratio (OR) 1.42 (1.01–2.0) and the need to have more economic-insurance information (tickets, invalidity, etc.) in relation to the illness (item 15) OR 1.51 (1.06–2.13). Three more needs (only borderline associated with the bivariate analysis) were associated with the use of CTs after adjustment: the need to receive more explanation on treatments (item 4) OR 1.49 (1.05–2.12), the need to

receive more comprehensive information (item 6) OR 1.65 (1.15–2.38), and the need for more attention from nurses (item 12) OR 1.84 (1.12–3.03). The need to be more reassured by relatives (item 20) was borderline, associated only at the bivariate analysis (20% vs. 25.1%, p = .102).

Table 3 shows the results for bivariate association between area-specific scores and the number of different CTs used ('intensity' of CT use). Although there is a tendency towards higher needs score for higher 'intensity' of CT use, no association was statistically significant neither at the bivariate nor at the multivariable linear regression analysis.

#### **Discussion**

Cancer patients have several different kinds of needs depending on the phase of the disease and the care process. Some of these needs are considered 'unmet needs' when a patient recognizes a gap between the level of service and support received, and the level that the same individual perceives is necessary to achieve optimal well-being [8,16,17]. Unmet needs include information and dialogue with clinicians [14,17–19], assistance/care [20,21], psychosocial support [17,19,22,23], spiritual issues [24], and sexual issues [25,26].

In this study, we have confirmed the presence among Italian cancer patients assisted by the Public Health System, of high percentages of unmet needs, particularly with regard to information and dialogue with clinicians, control of symptoms, and psychoemotional support deriving from the possibility to speak with people who have had the same experience [14].

The existence of a consistent number of unmet needs in patients diagnosed with cancer raises the opportunity, as argued by Michael Baum, to question ourselves, as clinicians and staff responsible for health policy, about what has gone wrong and what is missing from our daily practice [6]. Taking care of the unmet needs of cancer patients is a challenge in which clinicians, administrators, and researchers should be daily involved in an attempt to improve the health system.

In Europe and North America, a large number of studies have shown that many cancer patients turn to CTs to satisfy needs other than curative ones [5,27]. In particular, patients seek CTs for purposes of support that include improving general health conditions, supporting medical treatments, or treating psychological distress. We confirmed this tendency also in Italy [3].

In the present study, we particularly focused on unmet needs of cancer patients using CTs. Our survey shows interesting differences regarding perceived needs between patients who use and those who do not use CTs. In particular, patients using CTs had a higher percentage of unmet needs concerning more explanation of treatments and I 128 A. Bonacchi et al.

**Table 2.** Percentage Needs Evaluation Questionnaire affirmative answers distribution in patients using or not using complementary therapies;  $\chi^2$ -test \* < .05

		p-value					
NEQ item	Not using CTs	Using CTs	<b>P</b> articipants	chi-square test	Adjusted OR (95% CI)		
	% (N)	% (N)	% (N)				
I. I need more information about my diagnosis	37.3 (180)	37.0 (111)	37.3 (291)	.940	1.07 (.74; 1.55)		
I need more information about my future conditions	53.5 (255)	53.7 (161)	53.6 (416)	.955	1.03 (.74; 1.45)		
3. I need more information about the exams I am undergoing	33.6 (176)	41.0 (123)	38.2 (299)	.218	1.31 (.92; 1.87)		
4. I need more explanations on treatments	41.0 (197)	46.8 (139)	43.2 (336)	.110	1.49 (1.05; 2.12)		
5. I need to be more involved in the therapeutic choices	31.7 (151)	40.0 (120)	34.9 (271)	.018	1.36 (.95; 1.95)		
6. I need clinicians and nurses to give me more comprehensible information	31.9 (153)	38.0 (114)	34.3 (267)	.083	1.65 (1.15; 2.38)		
7. I need clinicians to be more sincere with me	30.2 (144)	31.1 (93)	30.6 (237)	.802	1.33 (.90; 1.97)		
8. I need to have a better dialogue with clinicians	37.2 (178)	44.4 (132)	40.0 (310)	.047	1.42 (1.01; 2.0)		
9. I need my symptoms (pain, nausea, insomnia, etc.) to be better controlled	35.9 (172)	40.7 (121)	37.8 (293)	.177	1.33 (.93; 1.96)		
10. I need more help for eating, dressing, and going to the bathroom	11.0 (53)	8.4 (25)	10.0 (78)	.238	1.08 (.56; 2.09)		
II. I need more respect for my intimacy	17.1 (82)	18.5 (55)	17.7 (137)	.629	1.39 (.98; 2.16)		
12. I need more attention from nurses	12.1 (58)	16.0 (48)	13.6 (106)	.116	1.84 (1.12; 3.03)		
13. I need to be more reassured by the clinicians	35.4 (169)	34.0 (101)	34.9 (270)	.686	1.18 (.81; 1.70)		
14. I need better services from the hospital (bathrooms, meals, and cleaning)	28.1 (134)	34.6 (103)	30.6 (237)	.057	1.41 (.97; 2.04)		
15. I need to have more economic-insurance information (tickets, invalidity, etc.) in relation to	36.4 (174)	46.1 (138)	40.1 (312)	.007	1.51 (1.06; 2.13)		
my illness 16. I need economic help	18.2 (87)	14.7 (43)	16.9 (130)	.204	1.08 (.65; 1.79)		
17. I need to speak with a psychologist	20.9 (100)	25.2 (74)	22.5 (174)	.170	1.13 (.74; 1.71)		
18. I need to speak with spiritual assistant	14.0 (66)	17.7 (52)	15.4 (118)	.171	1.28 (.79; 2.05)		
19. I need to speak with people who have had	` /	` '	` /	.299	, , ,		
my same experience	39.1 (184)	43.0 (125)	40.6 (309)	.277	1.03 (.72; 1.49)		
20. I need to be more reassured by my relatives	25.1 (120)	20.0 (59)	23.2 (179)	.102	.69 (.44; 1.08)		
21. I need to feel more useful in my family	32.3 (155)	27.1 (80)	30.3 (235)	.128	.99 (.68; 1.46)		
22. I need to feel less abandoned to myself	24.6 (117)	21.3 (63)	23.3 (180)	.292	.80 (.54; 1.19)		
23. I need to receive less commiseration by other people	25.7 (122)	27.8 (83)	26.5 (205)	.506	1.31 (.87; 1.96)		

CTs, complementary therapies; NEQ, Needs Evaluation Questionnaire; OR, odds ratio. Bold values are the OR significant after the adjustment.

Table 3. Area-specific needs score by 'intensity' of complementary therapies use (number of different complementary therapies).

	No CT use <i>N</i> = 483		Use of I CT N = 194		Use of 2 CTs N = 84		Use of ≥3 CTs N = 20		
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Adjusted p-value*
Informative needs	.37	(.36)	.40	(.35)	.42	(.36)	.37	(.34)	.103
Needs related to assistance	.13	(.25)	.15	(.25)	.14	(.25)	.09	(.15)	.099
Relational needs	.27	(.30)	.32	(.30)	.30	(.30)	.36	(.35)	.193
Needs for psychoemotional support	.27	(.31)	.24	(.31)	.23	(.31)	.20	(.27)	.998
Material needs	.24	(.29)	.26	(.28)	.28	(.28)	.43	(.41)	.183

CTs, complementary therapies; SD, standard deviation.

more comprehensible information. Patients with cancer express a desire for more information probably to have a more active role in treatment choices and to regain a sense of control in the face of an uncertain future and a passivity sometimes experienced in the acceptance of conventional

treatment. Miller *et al.* have found that the use of CTs helped patients with cancer having a sense of control over their illness or coping better with their illness [5]. Involvement of the patient in therapeutic choices and development of self-help attitudes is salient values of many CTs

<sup>\*</sup> Multiple linear regression.

Psycho-Oncology 1129

practitioners. In our survey, patients using CTs also showed a higher need to have a better dialogue with clinicians. This point was also a main finding of qualitative research on this topic [10]. Patients frequently report poor communication with oncologists, while longer available time and more attention to dialogue is often invested by CTs practitioners who offer more opportunities to talk, to ask questions, to be listened to, and to be emotionally understood. Communication between cancer patients and their physicians is very important on several different issues, including issues related to CTs use (e.g., side and toxic effects of some CTs and interactions with chemotherapy) [28,29]. It has been reported that barriers to unsuccessful communication on CTs, as perceived from the patient's point of view, are mainly physicians indifference or opposition toward CTs, physicians emphasis on scientific evidence, and anticipation of a negative response from the physician. Awareness, compassion, receptiveness, and adaptiveness have been considered communication skills useful to overcome these barriers [28]. Moreover, it has been suggested that when clinicians engage in conversations about CTs use, they could consider it as a coping strategy employed by the patient (e.g., diet modification as a problem-focused coping, meditation as an emotionfocused coping, and prayer or spiritual healing as a meaning-based coping) [30].

Complementary therapies users asked also for more attention from nurses, although in our study, we observed a low overall unmet need concerning attention from nurse staff (13.6%). Nurses in the oncology staff are often the professionals who spend more time in contact with patients and particularly inpatients. This time, however, can be affected both quantitatively and qualitatively from the burden of care that is frequently heavy. It would be very useful area of future research to conduct more in-depth studies to clarify the specific care aspects to which cancer patients refer when they ask for more attention from the nursing staff. At the moment, we can speculate that 'more attention from nurses' could include, for CTs users, a call for a broader and integrated vision of the person, another key point of CAM approaches, which usually emphasize the perception of the individual patient as a 'whole person' with multifaceted needs and concerns.

Patients using CTs also express, in a higher percentage, the need to have more economic-insurance information (tickets, invalidity, etc.) in relation to their illness. In Italy, medical assistance in Oncology Units of the Health Public System is offered free of charge; therefore, requests for economic-insurance information mainly pertain to abstaining from work and how to keep the job position. The higher demand for economic-insurance information in patients using CTs could instead be related to the fact that in Italy, the Health

Public System covers only part of the costs and only for a few types of CTs. Depending on how the health system has been set in different countries, there may be important differences on this need, and therefore, this result is not generalizable.

Surprisingly, spiritual and psychological needs are only slightly more expressed among Italian patients who turn to CTs, and the difference with those not using CTs is not statistically significant. This may be explained, at least partly, by the increasing attention paid in Italy in the context of the Health Public System to the psychological and spiritual issues, especially in the last 10 years.

Some of the needs in the present research that were expressed with higher percentages of affirmative answers in CTs users may be underestimated by clinicians in the public health system or considered 'complementary' to principal concerns about symptoms control and the possibility to cure or to prolong lives. 'Complementary needs' to main concerns may nevertheless be perceived as being relevant by some cancer patients, which may encourage them to turn to CTs with the aim not to replace but complement conventional therapies.

The correlations between specific unmet needs and CTs use described in this report, first of all, can give us information about the personality and the psychological experience of cancer patients who decide to use CTs. Moreover, even if medical and nursing staff could not be able to respond to all unmet needs of cancer patients who opt for CTs use; however, the observation of these correlations could suggest specific targets to strengthen skills and competencies in the oncology team either through the training of clinicians on this topics or through a more efficient and deeper collaboration with specialists in the field of psychosocial and spiritual support.

A limitation of the present study is the fact that we explored only those needs included in the NEQ that we adopted for the present survey. The existence of other possible 'complementary needs' should be explored in future studies using other questionnaires or open questions. Moreover, the existence of causal links between specific unmet needs and the use of CTs has to be confirmed through future prospective studies and through surveys focused on the evaluation of the effects of strategies and interventions to reduce the unmet needs.

In conclusion, our study shows interesting differences regarding perceived needs between cancer patients who use and those who do not use CTs. We think that unmet needs that are more expressed in CTs users should be known and, when possible, could be taken into account to improve the conventional care process and the efficacy of the relation between patient and oncology medical and nurse staff.

I I 30 A. Bonacchi et al.

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