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Original article

Complementary therapies in cancer: Patients' views on their purposes and value pre and post receipt of complementary therapy—A multi-centre case study

Dai Roberts^{a,*}, Charlotte Wilson^b, Chris Todd^b, Andrew F. Long^c, Peter Mackereth^d,
Jacqui Stringer^d, Ann Carter^a, Sam Parkin^e, Ann-Louise Caress^b

^a St Ann's Hospice, Manchester, England, United Kingdom^b School of Nursing, Midwifery and Social Work, The University of Manchester, Manchester, England, United Kingdom^c School of Healthcare, University of Leeds, Leeds, England, United Kingdom^d The Christie NHS Foundation Trust, Manchester, England, United Kingdom^e Beechwood Cancer Care Centre, Stockport, England, United Kingdom

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Abstract

Introduction: Complementary therapy (CT) use amongst cancer patients is common and increasing. Further understanding of why cancer patients choose to have CTs and their expected benefits is needed.

Methods: The aim was to compare cancer patients' expectations/attitudes regarding CTs pre- and post-CT. Multiple case study method (after Yin) was employed; this paper reports data from self-completed questionnaires completed before and after receipt of CTs by 113 patients from three cancer centres in North-West England (one hospice; one specialist cancer hospital and one community-based cancer support centre, all providing a range of CTs).

Results: Expectations regarding potential benefits of CTs primarily related to psychosocial issues (91 comments). Fewer patients sought CTs for physical symptom relief (30 comments). Attitudes to CTs were positive both before and after therapy. CTs typically met or exceeded patients' expectations (99/113, 88%). There was no indication that patients were turning to CTs due to disillusionment with conventional treatment. Most viewed CTs as 'something extra' (pre-CT 77/108, 68%; post-CT 86/113, 76%), rather than 'integral' to treatment (pre-CT 11/108, 10%; post-CT 19/113, 17%).

Conclusion: Patients had clear expectations of CTs, which were primarily related to psycho-social issues, both pre- and post-CT. Most patients were satisfied with CTs and perceived them as beneficial. However, few viewed CTs as integral to their cancer care. The data highlight a tension between needs or demand-led and evidence-based care provision. The exact role and unique contribution of CTs within cancer supportive care services needs further research.

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Keywords: Cancer; Complementary therapy; Palliative care; Expectations; Experiences; Attitudes

Introduction

Complementary therapy (CT) use amongst cancer patients is common and increasing, with usage figures ranging from 33% to 83% in studies across several countries [1–5]. There is also an increasing emphasis on integrative care, combining more

orthodox cancer care with the use of complementary therapies [6–8]. This has not, however, been matched with an increase in the understanding of their effectiveness or their benefits to cancer patients [9]. Indeed, the UK's National Institute for Clinical Excellence (NICE) Guidance on Improving Supportive & Palliative Care for Adults with Cancer has no key recommendations for core service provision of CT, largely owing to the lack of a quality research evidence base for these therapies [10]. Cancer patients have also been reported to have little prior knowledge or understanding of the purpose and value of CTs [11].

* Corresponding author. Tel.: +44 (0)1614983617.

E-mail address: droberts@sah.org.uk (D. Roberts).

A recent review summarised the expectations of CAM (Complementary and Alternative Medicine) users, from the wider literature, emphasising the wide ranging perceptions about the role of CAM [12]. Ernst concluded that the expectations of CAM users 'are currently not rigorously investigated' and that future studies should focus on specific aspects of CAM application [12]. Likewise, there are few data to indicate whether receipt of CTs modifies patients' views on these issues. Research is necessary to improve understanding of why cancer patients choose to have CTs, and how they value CT post therapy, to ensure that CT service development meets patients' needs. With this context, the aim of the work reported here was to undertake a comparison of cancer patients' expectations of and attitudes towards complementary therapies (CTs), before and after the experience of receiving such therapies. In this study, CTs were defined as therapies received (typically for symptom relief or to enhance well-being) alongside conventional cancer treatment, as distinct from alternative medicine, used in place of conventional cancer therapy.

Methods

A multiple case study was conducted, after Yin [13]. This was not an interventional study, but rather aimed to evaluate the perceptions and use of CT services as delivered within routine practice. Consequently, patients received different numbers of CT sessions/treatments, according to practice at each study site and personal preference. The study used a range of data sources (patients, therapists, key referrers and other health professionals, policy documents) and modes of data collection (one-to-one interviews, pre-CT and post-CT postal questionnaires, documentary analysis); this paper draws solely upon data from patient questionnaires completed before and after receipt of CT. The three cases were all centres offering CT to cancer patients in North West England:

Site 1 A hospice, with sites in three different locations, two of which offered in-patient, day therapy and outpatient services, whilst the third was a specialist rehabilitation unit which supported individuals with cancer from diagnosis onwards. Therapies offered were aromatherapy, massage, reflexology, Reiki, adapted Indian Head Massage, CranioSacral Therapy™ (<http://www.craniosacral.co.uk/>), homoeopathy and acupuncture. The number of sessions offered is individualised, but is typically 6–8.

Site 2 An acute cancer hospital; a tertiary referral centre for surgery chemotherapy, and radiotherapy, with an integrated CT service. Therapies provided included massage, aromatherapy, reflexology, Therapeutic Touch™ (<http://www6.miami.edu/touch-research/>) and relaxation techniques. Patients can receive either a single 'one-off' CT session or multiple sessions.

Site 3 A cancer care centre which provided psychosocial support through the provision of 12 week programmes for patients and carers. Therapies offered included reflexology, massage, aromatherapy, relaxation techniques and reiki.

In all centres, the CT received was patient chosen/negotiated with the therapist. At all sites, patients were at different stages in their 'cancer journey' (i.e. pre, post or currently in receipt of conventional cancer treatment), though more in Site 2 were currently in receipt of treatment due to the nature of this centre.

No suitable validated questionnaire existed. Consequently, a questionnaire was developed de novo to explore patients' expectations, attitudes and experiences of CTs. This was derived from an extensive review of the literature [9] and pooling of knowledge from within the study team and Project Advisory Group, which included a CT practitioner, a CT service manager, a CT researcher and a cancer service user. Topics addressed included rationale for choosing CT, overall views on CTs and expectations/perceptions of benefit regarding specific symptoms and problems. To ensure appropriateness and acceptability to patients, the questionnaire was piloted and revised accordingly before use in the main study. In order to understand patients' perceptions and expectations of CTs within the context of their socio-demographic background and cancer experience, data were also collected on demographic characteristics, mood state and health-related quality of life (HRQOL), using two validated instruments, the European Organisation for the Research and Treatment of Cancer, Quality of Life Questionnaire (EORTC QLQ-C30) and the Hospital and Anxiety Depression Scale (HADS) [14,15].

Questionnaires were given, over a 12-month period, to consecutive patients at each site for completion prior to receipt of CT. All those who completed and returned the pre-CT questionnaire were then sent a post-CT questionnaire within two weeks of receipt of CT/completion of the CT course.

Data analysis

Data were entered into SPSS V13.0 and analysed descriptively and using inferential tests (Wilcoxon matched pairs signed rank test and McNemar's test) to explore changes pre-post receipt of CT; a significance level of $p < 0.05$ was employed. Data from open questions were analysed using content analysis procedures after Morse and Field [16].

Ethics and governance

Site specific research governance and managerial approvals were obtained. Formal ethical approval was given by the relevant Local Research Ethics Committee. Participants gave written consent to participate and were assured of anonymity and confidentiality, which was supported by assigning each participant a unique identifier.

Results

Characteristics of sample

Pre and post CT questionnaires were completed by 113 patients across all three centres (mean age 54-year, SD 11.1; 93 females (82%); 110 'white British' (97%); 37(33%) secondary

Table 1
Patients' pre-post CT health-related quality of life (EORTC QLQ-C30).^a

EORTC score (1–100)	Median pre	Median post	<i>z</i> ^b	<i>p</i> ^b
Functional scales				
Global quality of life (<i>N</i> = 111)	50.0	50.0	−1.785	0.074
Physical (<i>N</i> = 103)	73.3	73.3	−0.336	0.737
Role (<i>N</i> = 108)	50.0	66.7	−1.572	0.116
Emotional (<i>N</i> = 107)	58.3	66.6	−3.253	0.001
Cognitive (<i>N</i> = 107)	66.7	66.7	−1.873	0.061
Social (<i>N</i> = 105)	50.0	66.7	−1.577	0.115
Symptom scales				
Fatigue (<i>N</i> = 104)	50.0	44.4	−0.800	0.423
Nausea and vomiting (<i>N</i> = 107)	16.7	0	−2.653	0.008
Pain (<i>N</i> = 106)	16.7	16.7	−0.059	0.953
Dyspnoea (<i>N</i> = 108)	16.7	0	−0.429	0.668
Insomnia (<i>N</i> = 109)	33.3	33.3	−1.288	0.198
Appetite loss (<i>N</i> = 108)	0	0	−2.525	0.012
Constipation (<i>N</i> = 106)	0	0	−1.989	0.047
Diarrhoea (<i>N</i> = 104)	0	0	−0.494	0.621
Financial difficulties (<i>N</i> = 111)	0	0	−0.571	0.568

^a Only patients who completed both the pre and post scale, that is, those with paired data, are included, hence *N*s < 113.

^b Wilcoxon signed ranks test.

school education or below, 76 (67%) higher than secondary school. These were typical of the CT populations at the three sites. Almost half the sample (*N* = 49, 43%) had breast cancer, whilst gynaecological cancers were also common (*N* = 13, 12%); cancer stage was not routinely recorded at all sites. However, a range of other cancers was also represented. Numbers were too small to meaningfully explore differences between individual study sites. Tables 1 and 2 report sample characteristics in relation to health-related quality of life and mood state before and after receipt of CTs. Statistically significant differences were found for four items within the EORTC score (emotional function, nausea and vomiting, appetite loss, constipation) and the HADS scale (both anxiety and depression). Given the study design, it is not possible to directly attribute these changes to receiving CT.

Expectations of CTs

Patients were asked, using an open question, about the main issues/symptoms that they hoped complementary therapies would help with (Tables 3a and 3b). Psychosocial issues predominated, appearing in 91 responses. A further eight patients indicated that they hoped CTs would help with 'general well-being'. Only 30 responses addressed

physical symptoms. Other responses (*N* = 8) related to meeting others in a similar situation (*N* = 2), 'holism'/'nurturing' (*N* = 3) and 'boosting immunity' (*N* = 3). Six patients gave no response.

The most common pre-CT reasons for choosing to receive CTs were to improve general, emotional and physical well-being, to assist in coping and because patients thought CTs would be a pleasant experience (Table 4). The least common pre-CT reasons for choosing to receive CTs were to 'fill a gap' in usual treatment, as an alternative to usual treatment or because something was missing from usual treatment (Table 6).

When patients were asked, using an open question, what their expectations of CTs were, the two most common categories of response were 'relaxation/relaxing experience' (*N* = 25 comments) and 'improving well-being' (*N* = 29, with one further patient expecting 'improved quality of life') (Tables 3a and 3b). 22 comments related to a potential impact on mood state (decreasing stress *N* = 12, reducing anxiety *N* = 8, improving mood/spirits *N* = 2). Another common category (26 comments) related to improved ability to deal with the cancer diagnosis/experience and 16 comments could be described as relating to 'holism'. Only 26 patients expected CTs to impact on physical symptoms/problems, 17 patients did not comment, whilst

Table 2
Comparison of anxiety and depression (HADS) scores pre- and post-CT.

	Anxiety pre (<i>N</i> = 107) ^a	Anxiety post (<i>N</i> = 107) ^a	Depression pre (<i>N</i> = 106) ^a	Depression post (<i>N</i> = 106) ^a
Median score	10.0	8.0	6.5	5.0
Range	1–20	1–20	1–19	0–16
'None' (%) (0–7)	36 (34)	45 (42)	59 (56)	76 (72)
'Borderline' (%) (8–10)	33 (31)	32 (30)	29 (27)	16 (15)
Clinically significant (%) (11–21)	38 (35)	30 (28)	18 (17)	14 (13)

Change in pre-post CT scores (Wilcoxon matched pairs signed ranks test). Anxiety: *z* = −1.98, *p* < 0.05; depression: *z* = −2.73, *p* < 0.01.

^a Only patients who completed both the pre and post scale, that is, those with paired data, are included, hence *N*s < 113.

Table 3a
Overall views regarding complementary therapy (CT) in the sample (N = 113).

	Number of comments
What is the main symptom/problem that you hope CT will improve? [pre-CT open-ended question]	
Psychosocial issues – of which	91
Mood disturbance (e.g. anxiety, depression, emotional problems)	48
Relaxation/reducing tension	29
Coping	14
Physical symptoms – of which	30
Pain	6
Musculoskeletal problems	6
Fatigue/lack of energy	5
Sleep disturbance	4
Treatment side effects	3
Back pain	2
Headaches	2
Breathing problems	1
Nausea	1
General well-being	8
Other – of which	8
Holism/nurturing	3
Boosting immunity	3
Meeting others in a similar situation	2
What is your main expectation of CT? [pre-CT open-ended question]	
Improved well-being (or quality of life)	29 (1)
Improved ability to deal with cancer diagnosis/experience – of which	26
Improved coping	12
Improved mental strength/positive thinking	6
Increased confidence (general/in ability to fight cancer)	5
Increased acceptance of situation	3
Improvement in physical symptoms/problems – of which	26
Muscle tension	11
Insomnia	5
Pain	4
Treatment side effects	3
Low immunity	1
Headache	1
Fatigue	1
Relaxation/relaxing experience	25
Improved mood state – of which	22
Decreased stress	12
Reduced anxiety	8
Improved mood/spirits	2
'Holism' – of which	16
Inducing calmness/contentment	8
Improved 'inner balance'	7
Providing 'healing'	1
Social aspect – of which	5
Providing 'respite'	1
Being a source of external help	1
Improving the situation for my family	1
Inducing feeling of 'being normal'	1
Reducing feelings of isolation	1
Cure/prevention of recurrence	2
No prior expectations (or don't know)	5 (1)

Table 3b
Achievement of expectations, perceived satisfaction and benefits (N = 113).

	N (valid %)
Did CT help you with issue/symptom you most hoped/expected it would?	
Yes	89 (81)
No	5 (5)
Unsure	16 (14)
To what extent did CT meet your expectations?	
Met them	43 (38)
Exceeded them	56 (50)
Did not meet them	1 (1)
Did not have any prior expectations	13 (11)
How satisfied were you with the CT(s) you received?	
Very satisfied	76 (68)
Satisfied	33 (29)
Neither satisfied nor dissatisfied	2 (2)
Dissatisfied	1 (1)
Very dissatisfied	0 (0)
How would you rate the CT(s) you received in terms of benefit?	
Of no benefit 1	1 (1)
2	1 (1)
3	10 (9)
4	23 (20)
Very beneficial 5	78 (69)
Would you recommend CT to others?	
Yes	108 (96)
No	0 (0)
Unsure	5 (4)
Would choose to have CT(s) in the future?	
Yes	102 (93)
No	1 (1)
Unsure	7 (6)

five indicated that they had no prior expectations and one stated 'don't know'.

Notably, two patients believed CTs had curative intent, one stating that they expected CTs to cure them and one that they would prevent disease recurrence. Other comments could be classed as relating to a 'social' aspect of CTs.

Attitudes towards CTs

Most patients saw CTs as "something extra", both before and after therapy. However, post receipt of therapy there was a modest increase in the number viewing CTs as "integral" to their treatment and a reduction in the number who were uncertain about the role and purpose of CTs (Table 5).

Most patients held positive attitudes towards CTs both before and after receipt of therapy (Table 6). Patients were significantly more likely to be committed and more accepting/less sceptical post-CT than pre-CT ($p < 0.0001$).

Most patients were either 'very satisfied' or 'satisfied' with the CTs they had received (Tables 3a and 3b), with comments presenting typical rationales for this:

'...they were relaxing and produced a feeling of well being'

'I had given up any hope of feeling happy and relaxed again. The therapy really helped to help me achieve relaxation and inner peace'

Table 4

Comparison of patients' pre-CT expectations and post-therapy descriptions of CTs.^a

	% pre	% post	<i>p</i> ^b
Expected/found it to be a pleasant experience (<i>N</i> = 113)	83	94	0.008
Expected/found it to be a reassuring experience (<i>N</i> = 85)	59	66	0.38
To help me to cope (<i>N</i> = 113)	83	73	0.04
To reduce one or more symptoms (<i>N</i> = 113)	54	37	0.005
To reduce side effects (<i>N</i> = 113)	41	27	0.01
Opportunity to talk to someone who understands my situation (<i>N</i> = 113)	60	62	0.89
Because there is/was a lack of alternatives to usual treatment (<i>N</i> = 113)	10	10	1.00
It is/was just something extra on offer (<i>N</i> = 113)	42	32	0.08
It was something available when I most needed it (<i>N</i> = 87)	59	47	0.11
Helped to fill a gap (<i>N</i> = 86)	31	17	0.02
Provided something that was missing from my usual treatment (<i>N</i> = 113)	17	43	<0.001
As an alternative to usual treatments offered for my condition (<i>N</i> = 113)	17	24	0.23
It provided something more than my usual treatment (<i>N</i> = 113)	33	57	<0.001
Improve general well-being (<i>N</i> = 113)	91	85	0.19
Improve physical well-being (<i>N</i> = 113)	74	52	<0.001
Improve emotional well being (<i>N</i> = 113)	87	81	0.12
Improve spiritual well-being (<i>N</i> = 113)	48	46	0.87
Expected/found it to be life enhancing (<i>N</i> = 85)	48	41	0.33

^a Only patients who completed both the pre and post scale, that is, those with paired data, are included, hence *N*s < 113.^b McNemar test.

Table 5

Views of the sample on the role of complementary therapies (CTs) before and after receipt of therapy (nb not paired).

Role of CTs	Pre-CT (<i>N</i> = 108) ^a <i>N</i> (%)	Post-CT (<i>N</i> = 113) <i>N</i> (%)
Integral to treatment	11 (9.7)	19 (16.8)
Something extra	77 (68.1)	86 (76.1)
Substitute for usual treatment	1 (0.9)	3 (2.7)
Unsure	13 (11.5)	4 (3.5)
Other	6 (5.3)	1 (0.9)

^a Excludes patients with missing items.

Table 6

Patients' attitudes towards CTs before and after receipt of therapy^a (figures in brackets = %).

Score	1	2	3	4	5	Wilcoxon
Uncommitted				Committed		
Pre (<i>N</i> = 96)	1 (1)	3 (3)	23 (24)	34 (35)	35 (36)	
Post	0	2 (2)	9 (9)	28 (29)	57 (59)	<i>p</i> < 0.001
Sceptical				Accepting		
Pre (<i>N</i> = 82)	3 (4)	4 (5)	16 (19)	31 (38)	28 (34)	
Post	1 (1)	3 (4)	6 (7)	23 (28)	49 (60)	<i>p</i> < 0.001
Indifferent				Curious		
Pre (<i>N</i> = 72)	3 (4)	0	10 (14)	23 (32)	36 (50)	
Post	0	2 (3)	17 (23)	25 (35)	28 (39)	<i>p</i> = 0.18
Negative				Positive		
Pre (<i>N</i> = 89)	3 (3)	0	9 (10)	22 (25)	55 (62)	
Post	1 (1)	1 (1)	4 (4)	20 (23)	63 (71)	<i>p</i> = 0.12

^a Only patients who completed both the pre and post scale, that is, those with paired data, are included, hence *N*s < 113.

'Allowed me to take time out and escape from my worries for a while'

'It was a beautiful time, when I was at the centre of care'

'It was such a pleasant experience'

'Had no expectations, but found it relaxing'

Only one patient was dissatisfied (Tables 3a and 3b), for the following reason:

'Didn't help my pain – actually increased it'

The therapist was regularly mentioned as being an important contributor to satisfaction with CTs, as the following comments illustrate:

'Because of the professional way it was delivered'

'Never had these particular treatments before. Exceeded my expectations. A lovely therapist who made me very relaxed, whole experience was great'

'The therapist gave me her complete attention and care'

Discussion

The data suggest that, within the context of cancer care, patients' pre-CT expectations from receiving CT were predominantly psychosocial in nature, including issues around mood disturbance, relaxation, reducing tension, coping and general wellbeing. Relief of physical symptoms was secondary in comparison. Pre-CT reasons for wanting to receive a complementary therapy were largely matched post therapy with a few exceptions (physical wellbeing, reducing symptoms, side effects, coping, and filling a gap). It is possible that the lack of prior exposure to CTs in most of the sample meant that they were unaware of the range of problems, both physical and psychological, for which CTs were offered at the sites. It is, however, notable that pre-CT physical symptom scores on the EORTC were relatively low in the sample as a whole (compared, for example with EORTC reference values [17]); this could suggest that those in greatest need of symptom relief were not necessarily receiving/coming forward for CTs.

These findings emphasise the importance of psychosocial support within cancer care. Whilst there is a sizeable body of research relating to cancer patients' psychosocial needs and studies of the efficacy of particular psychosocial interventions, NICE notes that 'no uniform agreement exists on the psychosocial support services that should be provided by relevant professional disciplines' [10]. Interesting questions both for those commissioning services and for future research are whether CTs are the most appropriate vehicle for the delivery of psychosocial support within a range of other services which also wholly, or in part, address psycho-social issues, such as specialist nursing (e.g. clinical nurse specialists, breast care nurses), psychology and counselling. Previous research in cancer care suggests that few therapists have formal training/qualifications in dealing with psychosocial issues, e.g. advanced communication skills training [18]; this has also been highlighted by NICE [10]. This raises questions about therapists' ability to deal with the psychosocial issues that arise, as well as regarding their training needs in this area. In this study, both satisfaction with therapy and therapist were high. There is clearly a need to understand whether patients' perceived improvements in psychosocial issues/symptoms are due to the therapy itself, the therapist delivering the CT or additional factors.

It is notable that few patients considered CTs as an alternative to, or substitute for usual treatment. This was further reinforced by the finding that few opted to receive CTs 'to fill a gap' or 'because something was missing' from their conventional treatment. This suggests that patients in the present study were not primarily motivated to use CTs through dissatisfaction with conventional treatments. This finding differs from a recently published literature review on patients' expectations from using complementary and alternative medicine, where the hope of influencing the natural history of the disease and disease prevention were the most prevalent rationales reported [12]. However, while many of the articles within that literature review were cancer specific, several were also from healthy or general populations. It is likely that one reason for these differential findings relates to the fact that within all three case study sites, CT

was offered as a routine treatment or supportive option – a situation that is being increasingly common within United Kingdom (UK) National Health Service (NHS) cancer care. This is in contrast to persons more generally seeking to access CT and where a deliberate search and/or decision is needed to explore alternative therapies. This is likely influenced by both the fact that patients who chose an alternative approach to their cancer care will not have been captured within our sample and by the forms of CT offered by the services studied (which were fairly typical of such services within the context of cancer supportive and palliative care service provision across the UK), with an emphasis on complementary therapy, rather than alternative medicine. However, the definition of complementary therapies within cancer supportive and palliative cancer care remains blurred, with many UK hospices for example offering a range of 'relaxation therapies', whilst others will offer such therapies as reiki and reflexology.

Most of the sample pre-CT regarded CTs as 'something extra' rather than perceiving them as 'integral' to their care. Although there was some change, the majority still considered this to be the case post-therapy. Such findings may suggest the need for a more integrative approach towards CT within cancer care, moving away from the 'complementary', or indeed 'alternative', terminology, though the concept of 'integrative' has also recently come under scrutiny [19,20]. Yet, there is increasing emphasis on providing cancer care which meets patients' needs [21,22]. The high level of satisfaction with CTs in the present study and evidence of their widespread use amongst people with cancer suggest that there is demand for and perceived benefit from CTs amongst patients with cancer [10,23,24]. NICE notes that decision-making regarding appropriate CT service provision in cancer is 'difficult', not least due to the lack of evidence of efficacy for many therapies [10]. There is clearly a tension for publicly or charitably funded services, particularly in the current economic climate, between provision of needs or demand-led services and decision-making based on other factors, such as cost-effectiveness or evidence of efficacy. As yet, the 'unique selling point' for CT is unclear, and hence so is the niche that they should occupy.

Limitations of the study

Only patients who were offered and subsequently received CT as part of their cancer supportive and palliative care were recruited to the study, and as such were a self selecting group. The study was focused within three recruitment centres in the North West of England and may not wholly reflect the diversity of CT services available within cancer care across the UK. The questionnaire was developed de novo and, although not primarily designed for such a purpose, would require further development and validation before it could be used more widely.

Conclusions

Findings from this study, indicate that both patients' expectations, and experiences after, CT provision during cancer care are limited in comparison with the range of symptoms (including

physical) and issues suggested as being amenable to therapeutic intervention involving CTs [25]. Our data suggest that patients have a clear idea of the role and contribution of CTs in their cancer care, and that this is primarily related to psycho-social support and well-being. Data from the present study may be of use in helping to identify appropriate, patient-generated ‘targets for treatment’ for CTs and also in selection/development of future outcome measures for use in CT research.

Pre-CT expectations were generally exceeded and the majority of patients were satisfied with CTs and perceived them as beneficial. However, most still viewed CTs as ‘something extra’, rather than as being ‘integral’ to their care, both pre- and post CT. The exact role and unique contribution of CTs within cancer supportive care services needs further research.

Authors

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Conflict of interest

None.

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