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**Individualised and complex experiences of integrative cancer support care:
combining qualitative and quantitative data.**

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Short Title: Cancer support care: combining quantitative and qualitative data

ABSTRACT

Objectives

The widespread use of complementary therapies alongside biomedical treatment by people with cancer is not supported by evidence from clinical trials. We aimed to use combined qualitative and quantitative data to describe and measure individualized experiences and outcomes.

Methods

In three integrative Cancer Support Centres (two breast cancer only) in the UK, consecutive patients completed the individualised outcome questionnaire Measure Yourself Concerns and Wellbeing (MYCaW) before and after treatment. MYCaW collects quantitative data (7-point scales) and written qualitative data and the qualitative data were analysed using published categories.

Results

782 participants, 92% female, mean age 51yrs, nominated a wide range of concerns. Psychological and emotional concerns predominated. At follow-up, the mean change (improvement) in scores (n=588) were: concern 1, 2.06 (95% CI 1.92-2.20); concern 2, 1.74 (95% CI 1.60-1.90); and wellbeing, 0.64 (95% CI 0.52-0.75). The most common responses to '*what has been the most important aspect for you?*' were 'receiving complementary therapies on an individual or group basis' (26.2%); 'support and understanding received from therapists' (17.1%) and 'time spent with other patients at the centres' (16.1%). Positive (61.5%) and negative (38.5%) descriptions of 'other things affecting your health' correlated with larger and smaller improvement in concerns and wellbeing respectively

Conclusions

In a multi-centre evaluation the MYCaW questionnaire provides rich data about patient experience, changes over time and perceptions of what was important to each individual with cancer within that experience. It is unlikely that meaningful evaluations of this complex intervention could be carried out by quantitative methods alone.

Keywords: Cancer, complementary therapies, qualitative, outcome measures, patient reports, oncology.

INTRODUCTION

An increasing number of people with cancer are coming to see the use of complementary therapies as an adjunct to hospital cancer treatment rather than as an alternative approach [1-5]. In this supportive role, complementary therapies are widely used after a cancer diagnosis and in the UK they are included in National Health Service (NHS) guidelines '*Improving Supportive and Palliative Care for Adults with Cancer*'[6]. These therapies may be accessed from individual practitioners, usually in the private sector, or from cancer support centers. The term 'integrative' is used to describe health care services that combine biomedical and complementary therapies. In the UK these centres are in hospital or community settings and may be funded by the National Health Service (NHS) and/or by charitable bodies. They aim to provide patient-centered care and physical, emotional, psychological and spiritual support.

Although complementary therapies are commonly used by people with cancer[7-9], randomized controlled trials of specific therapies in this population rarely demonstrate any benefit in terms of quality of life. Our experience of working in cancer support services leads us to suggest that this is because, for this population especially, the benefits of specific therapies are intertwined with the benefits of the therapeutic relationship and other contextual factors. Cancer support centres not only focus on providing complementary therapies to address the specific problems faced by people with cancer, such as side effects from treatment, but are also concerned with the environment and the manner in which the service is delivered. Consequently it has been suggested that cancer support care may best be evaluated using whole systems methods of research which combine quantitative and qualitative methods, focus on patient-centred outcomes, and acknowledge the necessity of iterative cycles of research[10]. This research strategy is similar to that promoted by the Medical Research Council (MRC) in its 'Framework for design and evaluation of complex interventions to improve health', which also acknowledges the importance of exploratory combined qualitative and quantitative data descriptive studies in order to understand the different components of complex interventions and the interconnections between them[11;12]. Although the MRC framework retains the 'definitive randomized controlled trial (RCT)' as its goal, it is acknowledged that there are some situations where RCTs may prove to be inappropriate, impossible, or inadequate and may need to be supplemented by observational studies [13]. It appears that cancer support care may be one of those situations. Whatever the research design chosen, appropriate outcome tools and methods are a vital resource for researchers in this field.

Methods for combining quantitative and qualitative methods in the context of large scale experimental or observational research designs are developing rapidly[14]. Such designs have only rarely, however, been applied to investigating cancer support care, an intervention which is both highly individualized and also difficult to control experimentally because of ethical issues [15,16]. This paper reports on the use of an outcome tool, the Measure Yourself Concerns and Wellbeing (MYCaW) questionnaire, which has been developed by a team of researchers, service providers and service users, specifically as a combined qualitative and quantitative data approach in this population. MYCaW is an individualized questionnaire which allows the respondent to specify their concerns, score the severity of these concerns and their level of wellbeing, and also write about important aspects of their lives and their

treatment experiences in their own words[17]. Repeated completion provides quantitative and qualitative data that can be compared at different stages of treatment. MYCaW is now being used in at least 10 UK cancer support centres and a few centres in North America and is reported to be popular because of its brevity, acceptability, appropriateness, and responsiveness to change[17;18] Details of the development of MYCaW, as an adaptation of Measure Yourself Medical Outcomes Profile, MYMOP, and the psychometric properties of these measures are reported elsewhere [17,20 21] Summarising and analyzing the written qualitative data collected with MYCaW can prove challenging, but recent work by Polley et al (2007), using the same qualitative data reported in this paper, has provided a structure for such analysis, thus promoting more detailed and comparative reporting of the qualitative data alongside the quantitative scores[19].

This paper reports the findings of service evaluations, carried out in three integrative cancer support centres in England, that utilized MYCAW to investigate the experiences of people with cancer and perceived changes in their concerns/problems and wellbeing over time.

METHOD

Settings and study population.

Data collection took place in three cancer support centres in England between 2004-2006. The data were collected as part of ongoing internal audit procedures, not as part of a research study and was not therefore subject to research ethics approval. All data were anonymised on-site before being shared and analysed for the purpose of this paper. Two of these centres were day centres run by Breast Cancer Haven (BCH) in London and Hereford. BCH works with the NHS and other healthcare professionals to promote and provide responsible and effective integrated breast cancer care. They offer support, information and complementary therapies to anyone affected by breast cancer. Their Haven Programme provides up to 12 hours of complementary therapies free of charge and is designed to help patients feel better and develop a healthier lifestyle. The third centre, Penny Brohn Cancer Care (PBCC, formally Bristol Cancer Help Centre) also promotes the integration of complementary and orthodox medical treatment, and runs 3 and 5 day residential courses, as well as a drop in service for the local population. It aims to provide physical, emotional and spiritual support through the use of complementary therapies and self-help techniques. All people with cancer are offered complementary therapies, irrespective of their cancer stage or prognosis or the type or stage of hospital medical treatment they are receiving. A more detailed description of the settings and methods of this study are published elsewhere[19].

The MYCAW questionnaire and its administration

The MYCAW questionnaire is completed with structured guidance on the first occasion and can be self-completed thereafter. It requires people with cancer to choose and write down in their own words 'one or two concerns or problems which you would most like us to help you with' and to score the severity of these concerns 'now' on a seven point scale - between 0 (not bothering me at all) to 6 (bothers me greatly). They also score their 'general feeling of wellbeing' on the same scale. On the follow-up questionnaire the respondent re-scores the original concerns and their wellbeing without seeing their original scores. In addition, there are two open

questions ‘other things affecting your health’ and ‘what has been most important for you?’ (see www.pms.ac.uk/mymop for full questionnaire).

All people with cancer attending the centres during the study period were given a MYCaW form to fill in. At BCH, the initial MYCaW form was administered at the start of their complementary therapy programme (of up to 12 hours therapies plus groups and classes), and the follow-up form was posted out after 10 hours of therapies or if the patient had not returned for 3 months. At PBCC, all people with cancer received the initial MYCaW form in the post before arriving for their 5 day residential course and completed it at their initial assessment, and the follow-up form was posted 4 weeks after the course.

Data Analysis

A merged dataset was constructed using anonymised data from all three centres, including both the quantitative MYCaW scores and the exact wording for each concern and the written answers to the open questions (qualitative data). Descriptive statistical analysis examined the distribution of gender, age and cancer site in the sample population (n=782). In view of the possibility that the score data can be argued to be on an ordinal rather than interval scale non-parametric tests were used throughout the analysis.

Qualitative data were first categorised via the process of a content analysis and a framework of categories was produced [19]; this current paper therefore represents the results of the proportions of responses in different categories and supercategories. All people with cancer were guided to state ‘one or two’ concerns, although some people still stated more than two; the majority of these extra concerns, however, fell within the same supercategory.

The ‘before and after’ scores for concern 1, concern 2 and wellbeing were analysed using Wilcoxon signed rank tests applying a cut-off value for statistical significance of $p=0.05$ (two-sided). Respondents were only included in this analysis if they had scored both concern 1 and wellbeing on both the first form and the follow up form (the second concern is optional). In addition, ‘change scores’ were calculated for each concern and wellbeing by subtracting the ‘before’ score from the ‘after’ score. With the BCH data, correlative analyses were carried out between these change scores and the number of hours of complementary therapies received or the duration of the therapy package using Spearman’s rank order tests.

For the open questions ‘other things affecting your health’ and ‘What has been most important for you?’, many respondents wrote multiple points which were all coded and the proportion of responses in each category was calculated. For ‘other things’ each point was categorized as a ‘positive’ or ‘negative’ effect and each respondent was assigned to one of four categories of ‘other things’ (responses containing ‘only positive’ ‘only negative’, ‘positive and negative’ and ‘nothing mentioned’).

The Kruskal-Wallis test was used to establish whether the concern or wellbeing ‘change scores’ were significantly associated with ‘other things’ happening in the lives of people with cancer, using the four categories described above. A series of Mann-Witney tests between each pair of the four sub-categories was conducted to confirm the differences in the change scores between sub-categories.

RESULTS

Response rates

Baseline MYCaW data were collected from 782 people with cancer between September 2004–January 2006 at BCH (London n=268, Hereford n=153) and between January 2004–December 2005 at PBCC (n=361). The overall response rate for the follow-up MYCaW form was 78% (n=607) comprising of 62% at BCH (n=260) and 96% at PBCC (n=347). A further 19 people were not included in the quantitative analysis as scores on the follow-up MYCaW forms were either missing or filled out incorrectly (BCH n=5, PBCC n=14), thus 588 people with cancer both responded to the MYCaW follow-up form and scored concern 1 and wellbeing correctly on both MYCaW forms (BCH n=255, PBCC n=333). Participants who did not return to BCH for therapies were sent a questionnaire to find out why and cited reasons such as: too far to travel, and they had to return to work so did not have time. Reasons for lack of returned posted forms at BCH included, lost in the post (approximately 5%), bereavement, too busy to fill it in, or changed address without informing the Havens.

Characteristics of participants and length of treatment

Overall the gender distribution was 91.7% female (BCH 100% and PBCC 77%) and the mean age was 51.43 (range 19-90 years). Cancer site for the combined data set was 79.2% breast (BCH 100% and PBCC 41.3%); 3.8% colon; 2.9% lung; 1.4% prostate; 17.4% 'others' and 1.5% unknown. At BCH the mean hours of therapy were 5.7 (range 1-16 hours) but because care is delivered to fit around medical treatment the overall period of care varied widely and the mean time between filling out the 2 forms was 6.5 +/- 3.4 months. At PBCC all people with cancer received a 5 day residential course and the mean time between filling out the first and follow-up MYCaW forms was 7 weeks +/-3.2 weeks.

Concerns and problems and wellbeing

The 782 respondents who completed an initial MYCaW form reported a total of 1729 concerns, as some recorded more than the two concerns they were asked for. Data were analysed using a published framework [19] and responses allocated to one of four possible supercategories (Figure 1).

Table 1 shows the MYCaW scores, before and after the treatment programme (described above), for all people who completed a follow-up questionnaire. All mean changes in scores were highly significant ($p < 0.0005$). Concern 1 (n=588) showed a mean change in scores of 2.06 (95% CI 1.92-2.20), concern 2 (n=533) a mean change of 1.74 (95% CI 1.60-1.90), and wellbeing (n=588) a mean change of 0.64 (95% CI 0.52-0.75). There was very little difference in change scores between the cancer centres, despite there being some differences in the types of concerns and cancer types described. The distribution of wellbeing scores showed a positive change for 53.7 % of patients, no change for 26.2% and a negative change for 20.1% of patients (Figure 2).

For the BCH data, no significant correlations existed between hours of therapies received as part of the treatment programme and change scores (Spearman's rank order test, $r = 0.026$, 0.068 and -0.027 for concern 1, concern 2 and wellbeing respectively), or between the duration of the complementary therapy package and the score changes (Spearman's rank order test $r = 0.019$, -0.019 and 0.069 for concern 1, concern 2 and wellbeing respectively).

What has been most important for you?

Out of the 588 participants, 508 responded to the open optional question, ‘*Reflecting on your time with [the centre], what were the most important aspects for you?*’ 981 items were reported, which were assigned to the ten published analytic categories, as shown in Figure 3. Negative feedback was only received from 2% of respondents and no noticeable difference in reporting frequency occurred between BCH and PBCC.

Other things affecting your health?

The follow up MYCaW questionnaire has an open question ‘*Other things affecting your health*’ with the subtitle of ‘*The treatment that you have received here may not be the only thing affecting your concern or problem. If there is anything else which you think is important, such as changes which you have made yourself, or other things happening in your life, please write it here.*’ The analytic framework for this written qualitative data consists of 17 categories within 6 supercategories[19]. Out of the 588 participants, 364 responded to the question and reported 498 items, that were assigned to 6 supercategories, (Figure 4). Each supercategory comprised of 2-4 categories, and the reporting frequencies were extremely similar between BCH and PBCC. Overall the most frequently reported category was ‘negative health issues related to cancer’. The top category in each supercategory is detailed in the figure, and is the same for each centre unless stated otherwise.

Each participant was classified as either ‘non-respondent’ (n=224), ‘positive only’ (n=173), ‘negative only’ (n=149) or ‘positive and negative’ (n=42). Overall 61.5% of the categorised items were classified as positive and 38.5% as negative. Where responses were ‘positive only’, this was associated with greater improvements in concern 1, concern 2 and wellbeing compared with the non-responders. In turn, the non-responders had more improvement than the ‘negative only’ responses. These differences were all statistically significant (Kruskal Wallis test $p < 0.0005$). This ranking was most pronounced with the wellbeing scores when compared to the concerns scores. The difference between positive responders and non-responders, and between negative responders and non-responders was confirmed by the Mann-Whitney U test on change scores for wellbeing ($p < 0.0005$ in both cases).

DISCUSSION

This multi-centre observational study has demonstrated the complexity of cancer support care as experienced by people with cancer and the ability of the MYCaW questionnaire to encompass and measure important facets of this experience. Using this individualised questionnaire, people with cancer nominated a wide range of concerns and problems as initial reasons for seeking help, amongst which psychological and emotional concerns predominated. Following treatment they not only rescored the ‘bothersomeness’ of these concerns but also added information about what had been the most important aspects of their care at the centre and what else had been happening in their life that may have affected their progress. We have illustrated how this combination of quantitative and qualitative data from 588 people with cancer in three centres can be analysed and presented in a concise and accessible manner.

Achieving high response rates in this population, many of whom were in a time of crisis and concomitant biomedical treatment is a difficult challenge, especially in a ‘real-life’ observational study that was carried out with few extra resources. The fact

that all eligible participants completed the initial form and 78% of these completed a postal follow-up confirms that MYCaW is both feasible and acceptable in this context. Following their treatment programmes, the initial highly bothersome concerns and problems improved by a mean of 2.06 (95% CI 1.92-2.20) for concern 1, and 1.74 (95% CI 1.60-1.90) for concern 2. Previous work with similar 7 point scales indicates that a change of over 0.7 – 1.0 is likely to be clinically significant and that the mean changes reported here are likely to be highly significant to the clients concerned[20-23]. The smaller change in wellbeing scores (mean change of 0.64, 95% CI 0.52-0.75), is to be expected when focused interventions are provided in the context of major distress or disability. In these situations complementary therapies may aim to prevent a deterioration in quality of life, rather than a positive improvement[24]. This small change in wellbeing also indicates that clients are scoring their own perceptions and are not misrepresenting their experiences through a desire to please. The nature of the concerns and the degree of change in concern and wellbeing scores are similar to those reported in other studies that have used MYCaW in cancer support centres[17;25] and in people with cancer consulting spiritual healers[18].

In this observational study design, it is not possible to prove cause and effect in a statistical manner but the qualitative data indicates that participants considered many aspects of the care to be important. Over a quarter of clients perceived the specific therapy as the most important feature and clients also valued feeling supported and cared for by staff and other clients and appreciated the other facilities offered.

The lack of correlation between the hours or duration of therapy at BCH and the degree of improvement in the concern score may be due to the individualised nature of the treatment offered. The therapy packages for people with cancer are tailored to the unique needs of each individual, taking into account their diagnosis, prognosis, MYCaW concerns, wellbeing and biomedical treatment schedule, and are reviewed as the programme progresses. Hence, while some may improve with a couple of hours of therapy or over a short time period, others make much slower progress. Concerns that are psychological and emotional are often complex in nature and may require many hours of counselling, life coaching or mind-body therapy. They may also require time between treatments for the patient to process the situation and make life changes.

Analysing and combining the quantitative and qualitative data collected by MYCaW illustrates how the contextual factors that were gathered using qualitative methods interacted with the quantitative outcomes of the main concerns. It is of some importance that there was such a strong association between positive and negative ‘other things’ happening in patients’ lives and the score changes they recorded. Those that reported a positive event improved more for both concerns and wellbeing than the non-responders, and the non-responders had more improvement than those reporting a negative event. Whilst this result may seem, from a lay perspective, self-evident, it demonstrates complex interactions that are important at the level of service provision which are often not taken into account in experimental research designs.

In this paper, we have reduced written qualitative data to categorical data which can then be analysed quantitatively. Being able to feed this qualitative data into an overarching analysis has the advantage of making such an analysis richer and more grounded in the whole experience of the person with cancer. However, it also results

in a loss of detail and language of the cancer patients' voices, because the primary qualitative data are not available to the reader. The qualitative data collected in this study is presented in more detail elsewhere [19] and we recommend that, at a minimum, reports of MYCaW data present some direct quotes that are assigned to each of the main categories. In addition, this written data, although often brief, is rich in meaning and significance, and is suitable for more in depth and conceptual analyses if resources are available. The written answers to the question 'what has been most important to you?' describe aspects of the experience of attending for care which were somewhat different to the initial focused concerns or problems. The responses demonstrate that both the therapy and the contextual factors are important to people with cancer and are vital for understanding the complex totality of good service provision in cancer care. The value placed on feeling supported and understood and on relationships with therapists, staff and other people with cancer have also been found in more in-depth qualitative studies of similar populations [4;26-29].

One of the limitations of the study, in terms of generalisability, is the over-representation of women with breast cancer in the sample. The type of concerns and the degree of benefit, however, was similar in both BCH centres and the PBCC where people have a range of cancer types. It is also of interest to note that the importance of psychological and emotional concerns found in this study has also been found in studies where male cancer patients have been well represented and that complementary therapies had a potentially important role to play in the helping male cancer patients communicate their need for comfort, emotional and psychological support [28]. Our evaluation is also limited by a relatively short period of follow-up observation: a common situation when resources are limited. Further work using MYCaW over extended periods of time would be useful, especially in view of the sequential phases of decision making and use of complementary therapies described by Truant & Bottorff (1999). Their study of women with breast cancer suggests that interconnected phases include '*getting something in place*', '*getting a personalised regime in place*' and '*fine-tuning a regimen to live with*' [30]. A longer term study could utilise a rolling series of MYCaW questionnaires to demonstrate changes in concerns and valued effects over time. Such studies may also throw more light onto the changes found by in-depth qualitative work, such as '*transformation*' [26] and '*unstuckness*' [31] which have not been elucidated in our work to date.

CONCLUSIONS

This study demonstrates that complementary therapies for cancer support can be a valuable adjunct for people with cancer, thus validating the inclusion of such therapy in clinical guidelines and care pathways. Almost half of the participants nominated psychological and emotional concerns, and others requested help with general wellbeing, physical problems and the side effects of orthodox treatments. Concerns were severe at the start of treatment and showed a clinically significant improvement at the end of treatment of 2.06 (for concern 1) and 1.74 (for concern 2) points on a seven point scale. Participants valued the specific therapy received and the support, understanding and positive relationships with both staff and other people with cancer. Their response to their complementary treatment was affected by many other aspects of their lives, both positive and negative. The use of the MYCaW questionnaire in a multi-centre observational design has provided rich and complex data about the patient experience and the changes over time, including perceptions of what was important to each individual within that experience. It is unlikely that a meaningful

evaluation of such a complex intervention could be carried out by quantitative methods alone. The combined qualitative and quantitative data approach employed in this study could be used, with or without more in-depth qualitative methods and/or methods of economic evaluation, to build an increasingly robust and generalisable understanding of the role of complementary therapies and cancer support care. In addition, using MYCaW could be an invaluable component in the internal service evaluation for any cancer support service.

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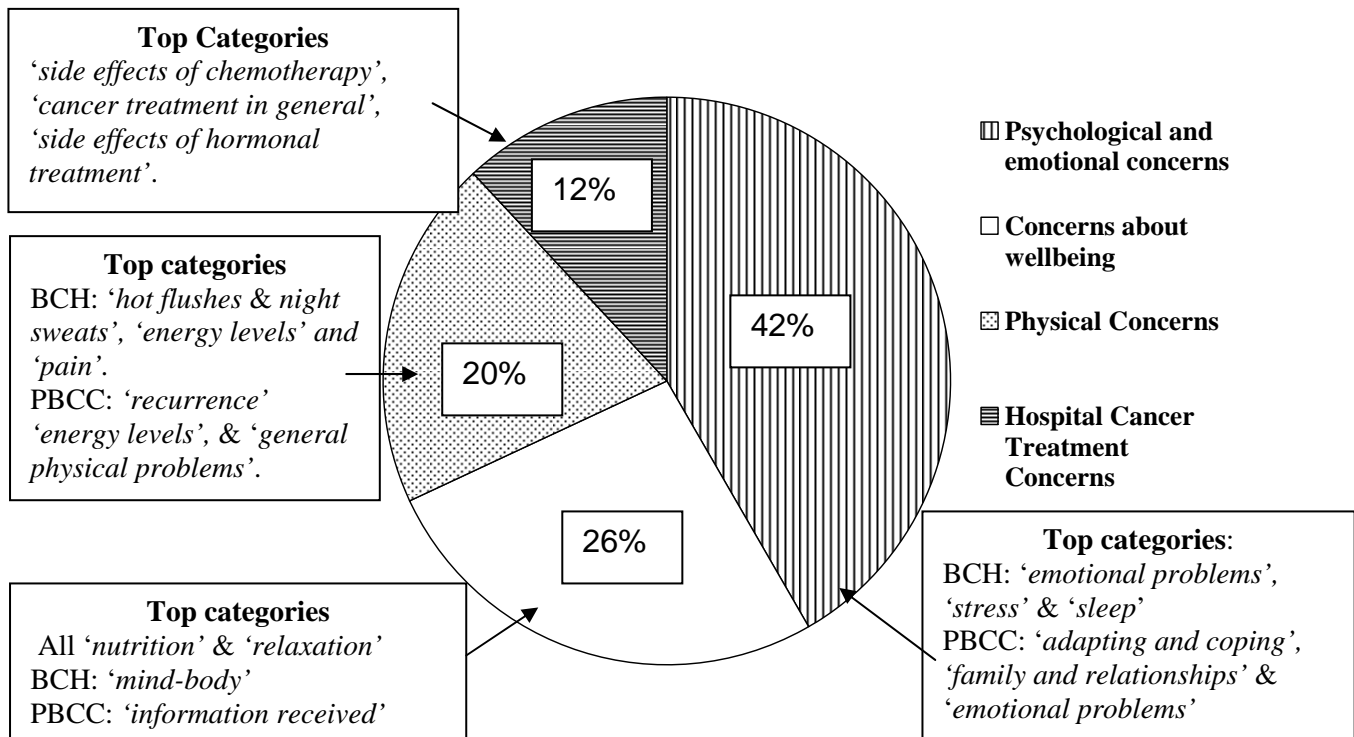
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MYCaW scores	Before Treatment	After Treatment	Change in Score
	Mean (SD)	Mean (SD)	Mean (95%CI)
Concern 1 (n = 588)	4.79 (1.20)	2.73 (1.62)	2.06* (1.92-2.20)
BCH (n = 255)	4.92 (1.09)	3.02 (1.68)	
PBCC (n = 333)	4.68 (1.26)	2.51 (1.54)	
Concern 2 (n = 533)	4.45 (1.24)	2.70 (1.58)	1.74* (1.60-1.90)
BCH (n = 228)	4.53 (1.18)	2.86 (1.69)	
PBCC (n = 305)	4.42 (1.25)	2.61 (1.47)	
Wellbeing (n = 588)	2.91 (1.32)	2.27 (1.32)	0.64* (0.52-0.75)
BCH (n = 255)	3.09 (1.26)	2.49 (1.38)	
PBCC (n = 333)	2.79 (1.33)	2.11 (1.24)	

Table 1. MYCaW scores, 0 (as good as it can be) to 6 (as bad as it can be).
*significant at $p < 0.0005$.

Figure 1: Types of Concerns reported by patients.



Types of Concerns and Problems: 782 patients reported 1729 concerns, which were analysed using a published framework[17]. The three most reported categories for each supercategory are detailed above

Figure 2. Distribution of score changes for concern 1, concern 2 and wellbeing.
(A positive score change denotes an improvement)

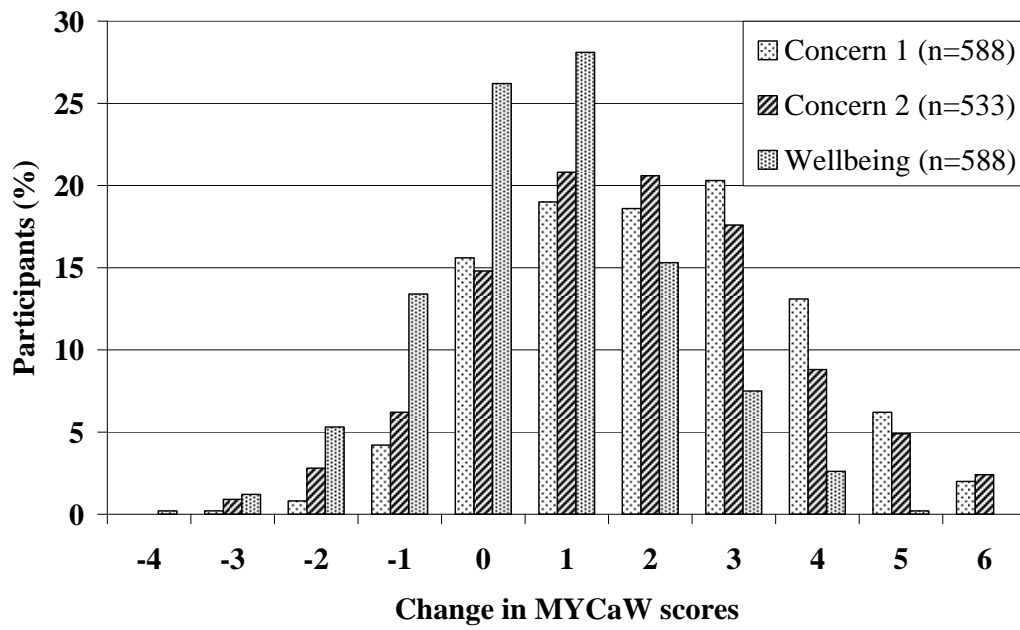


Figure 3. Reflecting on your time at the centre what were the most important aspects for you?

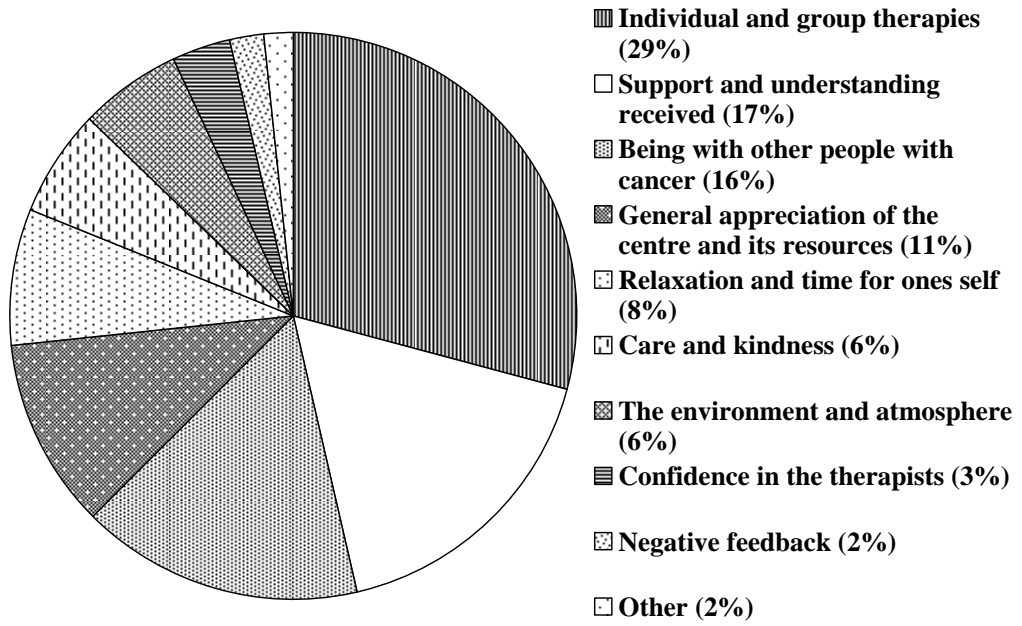


Figure 4: Other Things Affecting Health.

