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#### Research paper

# Complementary therapy for people with cancer; the patient's perspective



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#### ABSTRACT

Introduction: Despite widespread use, there remains a paucity of research exploring cancer patients' experiences of receiving complementary therapy treatment. We wanted to gain insight into the experiences of patients using a complementary therapy outpatient service offering aromatherapy, massage, reflexology and Reiki. At this London Cancer Centre, therapies are offered to patients as a self-referral service as part of their treatment pathway at any stage of treatment or follow up.

*Methods*: New patients (n = 96) attending the outpatient complementary therapy service for the first time were asked about their main concerns. The MyCaW (Measure your concerns and wellbeing) evaluation tool was used to collect data. Follow up MyCaW data from these patients was also collected after 4 sessions of complementary therapy. Patients were able to choose which therapy they wished to receive at each session.

*Results*: Patient reported outcomes after receiving 4 sessions of complementary therapies demonstrated significant improvements (indicated by at least a 1 point change in MYCAW scores) across a range of concerns. The greatest improvements were seen in relaxation, sleep problems, and pains/aches.

Conclusion: Qualitative comments collected from this evaluation indicate that complementary therapies can address both physical and emotional concerns often simultaneously and provide a unique therapeutic space for patients. Many patients have not had this experience before and this may introduce them to new methods of addressing complex multi dimensional issues resulting from living with a cancer diagnosis.

## 1. Introduction

There is increasing focus in cancer care on patient experience and quality of life both during and beyond treatment. The NHS national cancer strategy recognizes the importance of providing tailored individualised care to patients which support an enhanced patient experience and improve the quality of life for cancer patients [1]. Advances in cancer treatments can prolong patients survival; however, conventional treatments often result in debilitating side effects. These can be difficult for patients to tolerate; with a range of complex, often long lasting, emotional and psychological symptoms. Complementary therapies are widely used by cancer patients to alleviate this experience

A significant proportion of cancer patients seek some form of complementary therapy either during or after their cancer treatment [2–5] The term complementary therapy covers a wide range of different modalities. This evaluation was concerned with the range of complementary therapies provided to support cancer patients at the Centre involved with the study and includes; aromatherapy, massage, reflexology and Reiki The therapies are provided by specially trained

complementary therapists fully qualified and insured to practice who are employed by the Hospital Trust,. The service is provided within the UK National Health Service (*NHS*) and is predominantly supported by charitable funding. The Hospital Trusts own charity provided the initial funding to support one therapist practicing massage, reflexology and aromatherapy with a remit to provide supportive care for patients. The team has expanded since then as more funding has been made available. The choice of therapies offered reflects therapies which are well used by patients but also having few or no contraindications for patients undergoing orthodox treatment [6,7].

This service evaluation provides a means to demonstrate effective practice and sustainability. It is in accordance with the UK National Institute for Clinical Evidence (NICE) guidance on Improving Supportive and Palliative care for adults with cancer which recommends that services providing complementary therapies in the NHS contribute to the body of knowledge by evaluation and investigation of the effect and impact of therapies [8].

Understanding why patients choose to access complementary therapies in the NHS could provide valuable knowledge when planning

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service expansion and considering appropriate therapies to offer.

Complementary therapy is provided as one part of a wider supportive care service which includes access to information, a wellbeing programme, welfare and benefits advice and psychological and emotional support. Similar services operate at some other acute care hospitals across the UK [7,8] but distribution of services varies considerably [11]. This complementary therapy service, in common with others, has developed over a number of years and is a small and very well used resource. This Hospital Trust is a specialist centre for many types of cancer and treats patients from both the local area of London and across the country. In 2016 the team delivered over 4600 complementary therapy interventions to inpatients and out patients in cancer services and their carers as either one to one therapy sessions or aromasticks for relief of symptoms such as anxiety, nausea, and insomnia [12-15]. The majority of the therapy sessions were for inpatients who are supported throughout their hospital stay. Overall just under 800 aromasticks were given either separately or in addition to a one to one therapy. 1470 sessions of therapy were delivered to outpatients during this time.

The Measure your concerns and wellbeing (MYCaW) evaluation tool was chosen as it provides both qualitative and quantitative measures aimed to improve understanding of patients cancer experience [16]. It was designed specifically for complementary therapy interventions [17] and is easily administered during a therapy session. Its purpose is to capture the whole experience of receiving complementary therapy. It records perceived changes in symptoms and wellbeing pre and post treatment and also includes the therapeutic relationship and contextual factors [18]. This evaluation tool has been used to measure the effect of complementary therapy interventions in a number of previous studies [9,10,19]

#### 2. Methods

#### 2.1. Settings and sample

This cancer centre routinely provides patients with up to six complementary therapy treatments during their hospital treatment. Complementary therapy treatments available to patients include aromatherapy, massage, reflexology and reiki. Patients are able to select which complementary therapy(s) they would like to receive. They are offered written information on the therapies available and have the opportunity to discuss appropriate therapies before booking a session. All the cancer centre patients are offered complementary therapy treatment, irrespective of their disease stage or prognosis. For the purpose of this evaluation no additional data were recorded on the stage of disease or which stage of treatment patients were in when accessing the service. Patients make different choices about when to access complementary therapies. Some choose to have sessions concurrent with chemotherapy or radiotherapy treatments, or post- surgery, others prefer to have sessions during breaks between cycles of treatment or to use the sessions as post treatment rehabilitation. Data collection took place at the cancer centre between June 2014 and March 2016. The data were collected as part of a service evaluation, and research ethics approval was not required.

### 2.2. MYCAW questionnaire and its administration

All patients who were new to the complementary therapy service at the centre and were coming for their first outpatient session were included in this evaluation. Previous use of complementary therapy outside of this service was not recorded. Patients were told that the evaluation would be taking place when they booked their appointment. This information was given again at the start of the first appointment. Exclusion criteria were patients who had limited English and were unable to complete the form themselves (n=4), patients in a distressed state (n=4) patients unwilling, not interested in completing the form

(n=11). In addition to this excluded patients, 20 patients had limited time on their first appointment to receive therapy due to either arriving late, needing a very long consultation prior to treatment or interruptions to consultation such as becoming unwell during the consultation time. Of the patients unwilling to complete the form 2 patients gave the reason as being concurrently in receipt of other complementary therapies outside of this service so not being able to judge the impact of this service. The number of patients excluded in total was 41.

The impact of treatment on concerns of importance to the patients themselves was measured using the Measure Yourself Concerns and Wellbeing (MYCaW) [16]. The MYCaW is an individualised questionnaire that was developed for evaluating complementary therapies in cancer support care. MYCaW first form contains two patient-generated concerns and an overall measurement of wellbeing (see Fig. 4).

Patients rate concerns of importance to them and their overall wellbeing for the previous week using a seven point likert scale between 0 (not bothering me at all) to 6 (bothers me greatly). In addition, on the follow up form, there are two open questions 'other things affecting your health' and 'what has been most important for you?'(see Fig. 5) To limit the burden on patients, MYCaW was completed just twice. Patients completed the MYCaW with a cancer centre complementary therapist immediately prior to their first complementary therapy treatment, and then again immediately following their fourth complementary therapy treatment. The fourth session was chosen as the evaluation point as many patients do not complete 6 sessions or choose to take them over a long time period. Some patients, for instance, wish to save some sessions to use when they return to the centre for follow up after orthodox treatment is finished. Other reasons for not completing all 6 sessions may be due to logistics such as finding a suitable appointment time, transport issues and distance from the centre. Patients attend this specialist centre from a very wide geographical area. The average time period for patients to complete 4 sessions in this evaluation was just under 11 weeks, the median was 8 weeks and the longest time period was just over 1 year. Patients were only included in the service evaluation if they had scored both concern 1 and wellbeing on both the pre and post treatment MYCaW forms (completion of the second concern was not required for inclusion). Data were not collected on the number of patients who went on to have more sessions of complementary therapy after the 4 sessions were completed.

# 2.3. Data analysis

An excel dataset was constructed using anonymised data from cancer centre, including all MYCaW scores, the exact wording for each concern, and the written answers to the two open questions 'other things affecting your health' and 'what has been most important for you?' The distribution of gender, age, and cancer site was analysed using descriptive statistics. Patient-generated concerns were categorised according to previously published guidelines [16]. Pre and post treatment scores for concern 1, concern 2 and wellbeing were analysed using Wilcoxon signed rank tests. The change in score was calculated for each concern and wellbeing by subtracting each patient's pretreatment score from their post-treatment score. For the open questions 'other things affecting your health' and 'what has been most important for you?' responses were again coded according to published guidelines [16]. Patients' responses to 'other things affecting your health' were categorised as a 'positive' or 'negative' effect, with each patient assigned to one of four categories of 'other things' (responses containing 'only positive', 'only negative', 'positive and negative', and 'nothing mentioned'). Data was analysed using the Kruskal-Wallis test to evaluate whether changes in concern or wellbeing scores were significantly associated with 'other things' happening in the lives of patients, using the four categories described above.

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