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Research paper

Why cancer patients choose in-patient complementary therapy in palliative care: A qualitative study at Arokhayasala Hospice in Thailand

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ABSTRACT

Introduction: Cancer patients often choose complementary and alternative medicine (CAM) in palliative care, often in addition to conventional treatment and without medical advice or approval. Herbal medicines (HM) are the most commonly used type of CAM, but rarely available on an in-patient basis for palliative care. The motivations which lead very ill patients to travel far to receive such therapies are not clear. A qualitative study was therefore carried out to investigate influences on choosing to attend a CAM herbal hospice, to identify cancer patients' main concerns about end-of-life care.
Methods: Semi-structured interviews with 32 patients were conducted and analysed using thematic analysis. Patients were recruited from Arokhayasala, a Buddhist cancer hospice in Thailand which provides CAM, in the form of HM, a restricted diet, Thai yoga, deep-breathing exercises, meditation, chanting, Dhamma, laughter and music therapy, free-of-charge.
Results: The main factors influencing decision-making were a positive attitude towards HMs and previous use of them, dissatisfaction with conventional treatment, the home environment and their relationships with hospital doctors.
Conclusions: Patients' own perceptions and experiences were more important in making the decision to use CAM, and especially HM, in palliative cancer care than referral by healthcare professionals or scientific evidence of efficacy. Patients were prepared to travel far and live away from home to receive such care, especially as it was cost-free. In view of patients' previously stated satisfaction with the regime at the Arokhayasala, these findings may be relevant to the provision of in-patient cancer palliative care to other patients.

1. Introduction

Several reasons have been suggested as to why cancer patients use complementary and alternative medicines (CAM) [1–4] even whilst being treated with conventional medicine. A recent systematic review identified the most common reasons for using herbal medicines (HMs), the most prevalent type of CAM by cancer patients, which are taken mainly as self-medication [5]; patients hoped to improve physical symptoms, support emotional health, stimulate the immune system, improve quality of life, and relieve side-effects of conventional treatment. Surprisingly few studies cited achieving a longer life-span, and only one suggested dissatisfaction with conventional medicine, as reasons for using HMs [5].

The Arokhayasala Foundation at Wat (=temple) Khampramong is a Buddhist hospice that provides CAM, with a focus on HM, for in-patient cancer palliative care. 3638 patients have been treated since 2005 using general and individual HMs, a restricted diet, Thai yoga, deep-breathing exercises, meditation, chanting, laughter and music therapy and Dhamma (prayer and contemplation according to Buddhist philosophy) which comprises the temple regime [6]. Patients have reported perceiving benefit from this regime, although no clinical trial evidence was available to corroborate this [7]. This study aimed to explore reasons why cancer patients came to Arokhayasala, to clarify the reasons and concerns that lead them to travel far and live away from home in order to receive CAM palliative care. At Arokhayasala, HM is the main treatment but patients also appreciated the other activities of the temple regime, particularly the spiritual aspects, for enhancing quality of life [7].

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Table 1
Patients purposively sampled for the study.

Experiences of the temple regime		Attitude towards HM in general n[a] (no. of patients responding to questionnaire)		
		Negative	Neutral	Positive
Type of experience perceived	Beneficial effect	0 (0)	6 (59)	6 (151)
	Negative effect	0 (0)	5 (5)	5 (14)
	Neither benefit nor harm	0 (0)	5 (18)	5 (39)
Total		0	16 (82)	16 (204)

[a] No of patients sampled, based on attitudes towards HMs and experiences of the temple regime reported by questionnaire [7], out of the total number of patients expressing this attitude.

2. Methods

2.1. Setting

This study was conducted at Arokhayasala, Wat (=temple) Khampramong, Sakon Nakhon Province, Thailand. The temple was set up as a hospice in 2005, following the recovery from nasopharyngeal cancer of the Abbot of the Arokhayasala Foundation who used a combination of conventional and herbal medicine with meditation to aid his recovery.

2.2. Participants

2.2.1. Inclusion criteria

Patients resident at the temple who were 20 years or older, had a cancer diagnosis from their physician, spoke Thai or English, and gave informed consent to participate in this study.

2.3. Sample selection

The patients interviewed in this study were purposively selected according to their experiences of the temple regime and to attitudes towards HM in general (because HM is the main basis of the temple regime), in order to obtain a range of opinions representative of the attitudes expressed by patients who were resident at the hospice. A questionnaire was administered to potential participants as previously reported [7], which investigated these perceptions. No patients reported an overall negative attitude to HM, only positive and neutral attitudes, which was to be expected as all had chosen to attend the HM hospice. However, patients who had experienced the temple regime did report a range of perceived beneficial, neutral, and negative effects. After classification according to these attitudes and experiences, the samples were of unequal proportions, as shown in Table 1, but as they were representative of each type, a meaningful comparison of data among patients with different attitudes and experiences could be attempted.

2.4. Ethics, consent and permissions

Ethical approvals were obtained from the University of Reading Ethics Committee, UK (Project no 12/34), the Thai Traditional Medicine Ethical Committee, and the Ethical Committee of Sirindhorn College of Public Health Yala, Thailand (Project no. 094/2555). Organisational approval to collect data from patients was granted by the Abbot (July 8th 2012). Informed consent was gained from participants prior to data collection.

2.5. Data collection

Information leaflets were provided and explained to participants, and informed consent was obtained for participation in the study. A trained researcher (author BP) conducted face to face semi-structured interviews in the patients' own accommodation at Arokhayasala, for their convenience. Interviews took place between 5th January 2013 and 31st August 2014. All the interviews were audio-recorded and transcribed verbatim in Thai. Patient identifiers were changed to preserve anonymity. The transcripts were imported into N-Vivo v.10, a qualitative analysis software [8].

2.6. Data analysis

Transcripts were coded and analysed thematically in Thai. The five key steps of thematic analysis are: ***familiarisation, generating codes***, ***searching for themes***, ***reviewing themes*** and ***defining and naming themes*** [9]. For the first steps of analysis, interviews were read through at least twice to gain familiarity with the details and an overview of the gathered data. Data were then organised into meaningful groups using the method of Burnard et al. [10], who proposed a validation process of checking the coding of findings by asking an independent qualitative researcher (a trained qualitative researcher who was fluent in Thai and not involved in the study) to read the statements and identify themes according to the same coding system [10]. Three Thai transcripts were randomly selected and a comparison of interview codes developed by both researchers found 85.2% agreement. The next step was the generation of a thematic framework from the data and a rearrangement into themes which could be named and defined. Selected quotes were translated into English by author BP for use in reports and publications. Data saturation was reached after analyzing nine interviews.

3. Results

32 patients were sampled and interviewed as shown in Table 1. Participant characteristics and cancer types are shown in Figs. 1 and 2. 28.1% of participants were between 40 and 49 years old and the two most prevalent types of cancer were breast (22%) and liver (22%).

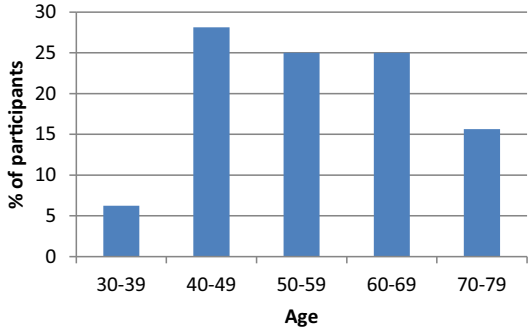

Fig. 1. Age of participants.

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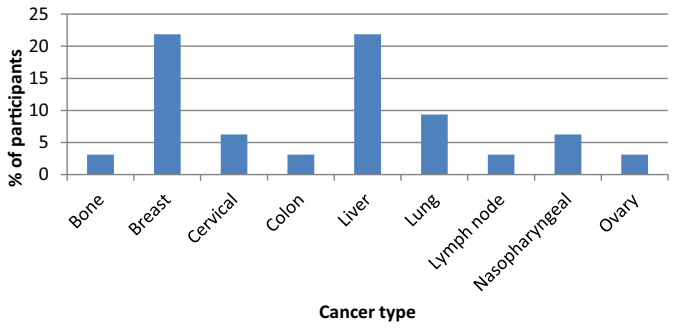

Fig. 2. Cancer types of participants.

3.1. Interview findings

Four main overlapping themes emerged from the data analysis to explain the reasons why cancer patients come to Arokhayasala. These were: (1) Patients' own experiences of using herbal medicines, (2) Patients' own experiences of using conventional medicine for cancer treatment, (3) Patients' relationship with their hospital doctors, (4) Patients' personality and home environment.

3.2. Patients' own experiences of using herbal medicines

Twenty six patients (81.2%) reported that they had used HMs prior to coming to the hospice. They cited three main reasons for using HMs: the majority (20/26) had regularly used them from a young age, with more than half (15/26) believing that HMs can alleviate minor ailments (e.g. fever, dyspepsia), and they used HMs following the example of their parents:

"I have seen the use of herbs by previous generations from the time of my great-grandfather. In his day western medicines were not as popular as they are now" (interview 15)

Herbal medicine use was also part of healthy diet prior to arrival at Arokhayasala:

"In daily life our meal must have at least one herb or fresh vegetable. I think fresh vegetables are better than cooked vegetables because they are high in vitamins" (interview 17)

Patients also perceived HMs to be safer because they are 'natural', and not as 'invasive' as conventional treatments such as chemotherapy and radiotherapy. Some participants who were educated to a tertiary (university) level (7/13) reported that they avoided taking conventional medicines because of their side effects, for example, they were aware that paracetamol can cause liver damage, diclofenac can cause peptic ulcer and muscle relaxant drugs can cause sleepiness.

"Herbal medicines come from nature and the chemical substances from herbs are not toxic for health. Although Western medicines are highly effective and I have heard of medicines such as paracetamol, but paracetamol can have side effects i.e. it can cause liver damage. So when I catch a cold I buy King of Bitters instead" (interview 18)

Patients who were familiar with HMs from a young age were strong advocates of using them for cancer. Three patients had taken herbal medicines together with conventional medicines to treat hypertension and diabetes and believed that HMs could help to control their medical conditions alongside conventional medicines. Accordingly, they had taken a combination of both without side effects, for about 10 years, without telling their physicians.

"I grew up among the wild and herbal medicines; therefore, I accepted treatments with nature as herbal therapy" (interview 24)

Although most patients reported benefits from taking herbal medicines, many still trusted conventional medicines to cure their cancer. Four patients reported undergoing chemotherapy and taking HMs to treat their cancer, again without telling their doctors, and reported positive test results such as improved blood count and liver function.

"I'm not sure because I took herbal medicines while having the chemotherapy. My blood test result was normal and I never postponed the chemotherapy" (interview 2)

3.3. Patients' previous experiences of using conventional treatments

Twenty patients had received conventional treatment for cancer before arriving at Arokhayasala. They had believed that conventional therapy would cure them but the cancer remained. Patients cited two main reasons for not continuing with conventional treatments: side effects of radiotherapy or chemotherapy, and worsening of symptoms or spread of cancer. Patients reported that radiotherapy had caused burns at the area of treatment ($n = 2$) and swelling ($n = 1$). Chemotherapy had resulted in numbness of the fingers ($n = 3$), alopecia ($n = 3$), anorexia ($n = 3$), nausea and vomiting ($n = 2$), pain ($n = 2$), insomnia ($n = 1$) and renal dysfunction ($n = 1$).

"Personally, I do not trust modern medicine, though I have used this method since the beginning. Despite all the chemotherapy and radiotherapy treatments I have had, my symptoms have not improved. Modern treatments have also damaged the muscles and nerves. In particular, the radiotherapy affected the nasal cavity and tendons in the neck. At that time I could not turn my neck because of pain. The lump had increased in size. My eyes and nose ran all the time – so I decided to come here" (interview 4)

Eight patients were disappointed with the results of conventional treatments: their symptoms had worsened, or their cancer had spread to other organs in the body.

"I had taken it [chemotherapy] three times. This [the first time] seemed a satisfactory result. However for the second time, before the treatment, the tumour was about 3.5 cm. After the treatment, its size was about 10 cm. The third time the doctor gave chemo to another side of the liver. After treatment, the cancer continued to spread" (interview 15)

Patients who had faith in conventional therapies felt very disappointed with the negative outcomes. Six patients reported that their cancer recurred or metastasized despite multiple treatments. For five patients, their doctors could not offer any further treatment for end-stage cancer, leaving them with nothing but a prognosis, the finality of which – and the lack of further available treatment – caused great stress to patients and their families:

"I had breast cancer 5 years ago and it had spread to my lungs. I have had an operation, 4 courses of chemotherapy and 10 courses of radiotherapy. I had hoped that the treatments would heal my cancer. In contrast, not only had my cancer spread to the lungs but I also have pulmonary oedema . . . I felt terrible" (interview 31)

3.4. Relationship with hospital doctors

When seeking alternatives, patients considered that they had the right whether or not to tell their hospital doctor of their

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decisions. Sixteen patients did not choose to tell the truth to their physician because they thought it was 'not necessary'. Seven patients had been told that the doctor could not offer any further conventional treatment, so they were 'entitled' to find other treatments. Only six patients told their hospital doctor of their intentions, and that was because they 'wanted to prove that herbal medicine at Arokhayasala could help cure their cancer'.

"I didn't tell a doctor because it was my life and I had a right to choose" (interview 29)

"I had to tell him the truth since he didn't give me further advice for my cancer treatment. I felt upset about this situation – I told the doctor I would go to Arokhayasala, and I also hope to check up with him when I finish the treatments, to prove Arokhayasala treatment works and by conducting more tests so that there is evidence of whether herbal medicines worked" (interview 2)

One of the more important explanations as to why patients did not tell the truth to their hospital doctors was that they did not want to 'offend' them. If patients disclosed that they were using herbal medicines, they thought the doctor might feel 'disappointed' with them. Other patients dare not tell their physician, often because they had changed their mind during conventional therapy and had taken herbal products during treatment. They were also afraid that their physician might prohibit them from taking herbal medicines.

"I thought . . . even though my hospital doctor was very generous . . . however, I still couldn't imagine how she would react if I told her the truth that I would like to stop taking chemotherapy because of side effects from it" (interview 2)

3.5. Personality and home environment

Decisions were influenced by internal factors, the patient's personality and experiences, and also external influences, arising mainly from the family and home environment.

3.5.1. Internal factors influencing the decision to come to Arokhayasala

Three internal factors were identified: ***fear of death***, ***perspectives on life*** and ***religious belief***.

Fear of death was one of the main motivations for looking for alternative cancer treatments:

"In fact I preferred to see a doctor but his response was too late . . . finally the doctor told me to stay at home and said sorry. That's why I came here – I didn't want to die" (interview 30)

Perspectives on life relevant to the decision to come to Arokhayasala involved worrying about the welfare of the rest of the family, and the desire to see children or grandchildren grow up:

"I came here since I didn't want to die. I have burden to take care my family as the main breadwinner" (interview 6)

Religious belief was another reason cited for visiting Arokhayasala, as they expected to gain merit at the end of their lives by following the Buddhist pathway. They also believed it could improve physical health.

"My daughter knows I love making merit as I always give alms to a Buddhist monk every morning at home. I think this is one of my daughter's reason to bring me to treat cancer here" (interview 8)

3.5.2. External factors influencing the decision to come to Arokhayasala

The four external factors identified were concerned mainly with the home environment. These were: ***finance, pressure from family members, testimonies from former patients*** **and** ***recommendations by hospital doctors.***

Finance was an important consideration, not because of the cost of treatment at Arokhayasala, which is free of charge, but because conventional therapy was so expensive and some patients were in debt because of it. Free cancer treatment at Arokhayasala was therefore very appealing to patients who could not afford to pay for any further conventional medicine. Some patients, especially those from Laos (patients travel from other neighbouring South East Asian countries to Arokhayasala), were very poor and could not afford expensive cancer treatment:

"Of course, I didn't have enough money I was in debt since my previous treatment with conventional medicine" (interview 31)

Pressure from family members to come to Arokhayasala was common, sometimes even when the patient did not want to. Family members searched for information from many types of sources for example, internet (22), books (11), televisions (10), radio (5), newspaper (2).

"I thought my hospital doctor could cure me but now my cancer has metastasised to the lung. My husband and my son did not trust conventional treatments and my daughter told me to come here even though I did not want to come" (interview 31)

Testimonies from family members or friends who had received beneficial effects from treatment there were an important influence on the decision to come to Arokhayasala.

"Based on my husband's experiences of using herbal medicines for curing cancer [at Arokhayasala]*, I believe herbal medicine can treat cancer" (interview 1)*

Recommendations from hospital doctors were surprisingly common. Three physicians referred their patients to Arokhayasala. Whether this was because they believed that the therapy would be effective, or simply wanted to offer hope, was not known. Patients accepted the suggestions because they did not want to die, and did not have any other choices.

4. Discussion

In-patient palliative care using CAM is uncommon, although cancer patients do use herbal and nutritional products, usually on a self-medication basis, while being treated on an outpatient basis [11]. Therefore little is known about why patients decide to travel and live away from home to undergo this type of treatment. Arokhayasala is becoming increasingly popular in Thailand and neighbouring South East Asian countries, and research into its methods is encouraged by the Abbot of the temple and supported by the Thai government as part of an initiative to use traditional medicine more effectively. Patients' perceptions of the therapies at the hospice have been explored and found to be mainly positive [7] but the reasons why they decided to visit the temple in the first place are not clear. We therefore decided to investigate these reasons and also explore any link between the reasons for coming and their actual experiences of the hospice regime.

The study found four main themes which influenced patients' decisions to come to Arokhayasala. They were: previous experiences of taking herbal medicines, previous experience of taking conventional medicines for cancer, relationship with hospital doctors, and personality and home environment (internal and external).

Arokhayasala provides CAM treatments for cancer patients without charge, including supplying HMs even after discharge, and this was an important factor in the decision to visit. It is a Buddhist temple, and this was also significant: patients wished to prepare for a peaceful death by 'making merit' as part of the Buddhist way of life.

Thai people frequently use herbal medicines in their everyday life and this familiarity means that they usually have a positive attitude towards using it for self-management of minor illnesses

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[12]. We found that participants had already experienced the use of herbal medicine and were not concerned about adverse effects or drug interactions. Within the theme of relationship with hospital doctors, we found that the disclosure of HM use to conventional doctors was not routine, and this seems to be common in Thai culture. Only 18.8% of patients told their hospital doctor, and this was because they wanted to 'prove' to him/her that the herbal medicine approaches at Arokhayasala could help them. Another 50% thought it was the patient's right to choose and it was not necessary to tell them. Previous studies have reported that between 59% and 76% of patients did not inform their healthcare team that they were using herbal medicines [12–14]. This was because they did not want to be prohibited from using them [15] or were concerned about what the doctor may think about the use of other therapies. In contrast, other studies have reported that 62% of patients had disclosed their CAM use [16] and 66.3% of patients had discussed it with their doctors [17]. This was attributed to the fact that the patients consulted were aware of the risks of taking HMs at the same time as conventional drugs [17]. Personal factors, and especially the home environment, were also major influences on patients' motivation to come to Arokhayasala. Previous studies have also suggested that friends and family are important in the decision for cancer patients to use CAM [24]. It was interesting that patients did not mention clinical evidence as a reason for using CAM, and despite the lack of proven efficacy some patients were referred to Arokhayasala by their hospital doctors. This could be due to the extensive use of HMs in Thailand and their acceptance by most of the population, including health care professionals and thus presents an interesting paradox that warrants further research to understand this social behaviour.

Negative effects from conventional treatments such as chemotherapy or radiotherapy influence patients to use CAM [3,18,19], as we have also found. A lack of further options and anxiety about dying leads to mental health challenges [20–23] and fear of death played a major role in making the decision to come to Arokhayasala to improve health and prepare for a peaceful end.

4.1. Study limitations

During data collection, author BP was acting as a member of staff at the hospice, which may have influenced the course of the interviews. Although this could be considered as bias, it has been suggested that the more closely the researchers are engaged with the environment in such studies, the more accurate the information that can be gained [25,26].

5. Conclusion

Our findings showed that patients' own perceptions and experiences were more important in making the decision to use CAM for in-patient palliative cancer care than scientific evidence of efficacy or recommendation by healthcare professionals, even though referral did sometimes occur. Patients were prepared to travel far and live away from home to receive such care, especially as it was cost-free. The main factors influencing decision-making were a positive attitude towards herbal medicines and their own previous use of them, dissatisfaction with conventional treatment, the home environment and a poor relationships with hospital doctors. In view of patients' previously stated satisfaction with the CAM therapies at Arokhayasala [7], these findings may be relevant to the provision of in-patient cancer palliative care to other patients. They may also help healthcare professionals to understand that cancer patients need support and to have a good relationship with their doctors during conventional treatment. The referral of patients with terminal cancer to CAM hospices may be appropriate, to give kindly support and holistic treatment when nothing further is offered by conventional medicine.

Although this study was conducted in a specific setting and the results therefore cannot be extrapolated directly to other situations, it is the first time that an assessment of why cancer patients choose in-patient palliative care has been carried out and provides a basis for further studies in other settings.

Authors

All research done by the authors.

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Conflict of interests

None.

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