



# 'Thinking outside the box': complementary and alternative therapies use in paediatric oncology patients

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## KEYWORDS

Complementary therapies;  
Alternative therapies;  
Paediatric;  
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**Summary** The aim of this study was to determine the prevalence of complementary and alternative medicine (CAM) use among children with cancer who had received or were receiving treatment at a large hospital in the UK, including the identification of the most commonly used therapies and parental motives for doing so. Using a cross-sectional survey design, questionnaires were sent to parents of paediatric patients diagnosed with cancer. Of the 49 respondents, 32.7% reported using some type of CAM. The most commonly used therapies included multivitamins, aromatherapy massage, diets and music as therapy. Most children had used more than one therapy. Many of the factors that motivated parents to use CAM were related to helping or supporting their child's medical treatment. The main benefits identified from using CAM included increased confidence, pain relief and relaxation. The longer the time since diagnosis the more children tended to use CAM. The reasons for parents not using CAM included the child doing well and therefore not seeing the need for CAM use; not being aware of CAM; CAM not being offered and lack of information available. Parents identified a need for more information to be available both at ward level and for information about CAM to be discussed by medical staff, particularly at the start of treatment. The results indicate that CAM is frequently used by children and young people with cancer and that their use plays a substantial role in helping children through their conventional cancer treatment.

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**Zusammenfassung** Ungewöhnliche Wege gehen: Anwendung Komplementärer Therapien bei onkologischen Pädiatrischen Patienten

In dieser Studie sollte untersucht werden, in welchem Ausmaß Methoden alternativer Medizin bei krebserkrankten Kindern angewendet wurden, die in einem großen Krankenhaus in Großbritannien behandelt worden waren oder noch behandelt wurden. Die Untersuchung umfasste diejenigen Therapien, die am meisten verbreitet sind. Außerdem werden die Motive der Eltern erforscht, die zur Wahl der entsprechenden Therapien geführt hatten. Nach den Vorgaben repräsentativer Auswahl erhielten die Eltern von Krebspatienten im Kindesalter Fragebögen. Die Auswertung der 49 zurückgeschickten Fragebögen ergab, dass 32.7% der Befragten alternative Heilmittel oder -methoden in irgendeiner Form einsetzten. Am häufigsten wurden Multivitaminpräparate, Aromatherapiemassage, Ernährungspläne und Musiktherapie genannt. Die meisten Kinder hatten mehr als eine Therapie erfahren. Die betreffenden Eltern wurden vielfach von dem Wunsch geleitet, die schulmedizinische Behandlung ihrer Kinder helfend zu unterstützen. Als hauptsächlichen Nutzen des

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Einsatzes alternativer Therapien nannten sie wachsendes Selbstvertrauen, Schmerzlinderung und Entspannung. Je mehr Zeit seit der Krebsdiagnose verstrichen war, desto mehr Kinder neigten zur Anwendung alternativer Therapien. Verschiedene Gründe wurden genannt, wenn die Eltern keine solche Heilmethoden einsetzten: dem Kind ging es gut, sodass keine Notwendigkeit für ihren Einsatz gesehen wurde; man wusste nichts von alternativer Therapie, sie wurde nicht angeboten; Informationen dazu waren nicht erhältlich. Eltern stellten ihren Bedarf an mehr Information heraus. Dies bezog sich sowohl auf die Situation im Krankenzimmer selbst als auch auf Gespräche mit medizinischem Fachpersonal, hier besonders am Beginn der Behandlung. Die Ergebnisse der Studie zeigen auf, dass alternative Therapie bei Krebspatienten im Kindes- und Jugendalter häufig eingesetzt wird und dass ihre Anwendung eine wesentliche Rolle bei dem Bemühen spielt, die betreffenden Patienten über die Zeit ihrer konventionellen Behandlung hinweg zu unterstützen.

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## Introduction

### Complementary and alternative medicine use in adult cancer patients

The demand for complementary and alternative medicine (CAM) as an approach to cancer treatment is considerable among cancer patients, with increasing numbers of adults seeking some type of CAM in conjunction with their mainstream medicine (Walker and Anderson, 1999). In the UK, estimates have ranged from 32% in patients' undergoing radiotherapy (Maher et al., 1994) to 16% in unselected oncology patients (Downer et al., 1994). According to Cassileth and Chapman (1996) this increase in popularity could be due to the increasing incidence of cancer in addition to the lack or absence of any apparent gains from conventional treatment which is therefore encouraging people to seek out other treatments.

Patients with cancer have described both physical (more energy, reduced feelings of nausea) and psychological (feeling calmer, emotionally stronger and more optimistic about the future) benefits from using CAM (Downer et al., 1994). Oneschuk et al. (2000) investigated the use of complementary therapies among 154 advanced cancer patients referred to palliative care services. The conclusions drawn from the data highlight the reasons for patients using complementary therapies which included symptomatic relief/improve survival; to cure their cancer; receiving pressure from family and friends; negative experiences with conventional treatments, in addition to negative experiences with health care professionals. Poor response or side effects generated by conventional oncology treatments was also a factor. Other cancer patients have reported benefits from such use, including a reduction in anxiety, pain, mobility, and tiredness,

in addition to improvements in feelings about the future, their appearance, concentration and mood (Corner et al., 1995).

It can therefore be seen that the use of complementary therapies is prevalent among the general adult population and for the majority of patients with cancer 'hope' is an important issue. Furthermore, it appears that relief and control of symptoms is an additional factor towards using complementary therapies.

### Complementary and alternative medicine use in paediatric oncology

In the UK, there are no studies focussing on either the extent of, or parental reasons for, the use of CAM among children with cancer. However, studies have been conducted in relation to its use in the USA (Friedman, 1997; Fernandez et al., 1998; Kelly et al., 2000); Canada (Bold and Leis, 2001); the Netherlands (Grootenhuis et al., 1998), and Australia (Sawyer et al., 1994).

Studies in children and young people with cancer are generally not as well-researched as in adult oncology patients. However, those studies which have been conducted over the past 20 years, have indicated that a variety of CAM therapies among children with cancer are used. In addition, these studies indicate an increase in the use of CAM in children and young people with cancer. For example in an early US study by Faw et al. (1977), 9% of parents indicated that they had used some form of complementary or alternative therapy with their children, whereas nearly 20 years later, levels of use had increased to 46% (Sawyer et al., 1994). The differences in percentages could be attributed to inconsistent definitions and types of therapies that were used in these studies, differing data collection methods or cultural

differences. It is questionable, therefore, whether such percentages can be conclusive. Hypnotherapy, mental imagery, relaxation and vegetable juices were shown to be the most commonly used CAM therapies (Sawyer et al., 1994).

A large-scale population based study of the use of CAM in children with cancer in Canada (Fernandez et al., 1998) found that 42% of paediatric patients ( $n = 366$ ) used some form of CAM. The most common reasons for using CAM, similar to the study by Sawyer et al. (1994), was to do everything possible and to 'boost' the immune system. Other reasons included, curing the cancer, to give 'softer' treatment, to slow the progression of the cancer and to use a more holistic approach. The main alternative therapies used included herbal teas, plant extracts, and therapeutic vitamins whereas the main complementary therapies used included relaxation strategies, massage and therapeutic touch (Fernandez et al., 1998).

A study conducted by Kelly et al. (2000) in the United States, aimed to determine the prevalence, modalities and determinants of use of unconventional therapies among children with cancer receiving conventional treatment. It demonstrated that 84% had used at least one unconventional treatment ( $n = 75$ ). Parents generally felt that it was part of their job to provide what the child would need to reach adulthood in good condition. This study highlights the need for health professionals to offer parents and patients the best current information available regarding unconventional therapies.

Grootenhuis et al. (1998) in their study in the Netherlands found that the most important variable with regards to parents' use of alternative therapies was if their child had cancer with low survival chances. Findings showed that 31% had used/were using alternative treatments, 46% of which were families of children with cancer who had suffered a relapse and 16% were families of children with cancer in remission.

More recently in Canada, Bold and Leis (2001) aimed to investigate the prevalence of unconventional therapy use among children with cancer by using a cross-sectional survey design with semi-structured telephone interviews. This study used a sample of 44 parents of children aged 14 years or younger when diagnosed with cancer. The key outcomes from this study included 36% of families reporting use of unconventional treatments for their child's cancer, the most popular therapy being herbal remedies (47%), and with 21% considering CAM use. The main reasons given for such use included complementing their child's conventional treatment, coping with side

effects, making the child stronger and stopping the cancer.

It is evident therefore that CAM plays an important role in the care of children with cancer (Bold and Leis, 2001). However, discrepancies between studies create certain drawbacks in the interpretation of findings. It is also interesting that parents are deciding to use CAM for their children for similar reasons as in adult oncology patients (Downer et al., 1994; Ernst et al., 1995; Oneschuk et al., 2000). Although there has been a growth in the use of CAM among children with cancer, no studies have been published in the UK regarding use of CAM in children and young people with cancer. Thus, the aim of this study was to assess the prevalence and motives around the use of CAM among children with cancer receiving conventional treatment through their parents' assessment. For the purposes of the current study, CAM is defined as 'diagnosis, treatment and/or prevention which complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual frameworks of medicine' (Ernst and Cassileth, 1998, p. 777).

## Methodology

A descriptive cross-sectional design was used for the purposes of this study. Proxy assessments were used to obtain information regarding children's use of CAM. Although it is acknowledged that information could have been received from some of the older children, for data collection standardisation purposes only proxy assessments were obtained. A descriptive questionnaire was developed by the authors, based on a review of the literature. The questionnaire was divided into three sections. The first section related to the child and family's sociodemographic characteristics. The second section included asking parents if they used any form of CAM, and if yes which therapies they used for their child and how much they felt their chosen therapies had helped their child, using a rating scale from 1 to 10 (with '1' being 'not helpful at all' and '10' being 'very helpful'). In the third section parents who were using some form of CAM for their children were asked to identify their motives for using a particular therapy. They were also asked where they had learnt about the therapies, the frequency of CAM use and whether they would recommend the therapy to other parents. Space for comments was also included in each item. Two open questions were also included in the ques-

tionnaire. These were asking parents to specify their reasons for not using CAM (if they did not use CAM) or the perceived benefits of using CAM (if they were using CAM).

## Procedures

Prior to commencing the study, meetings were held with senior staff nurses and consultants in the oncology unit where the study would take place. Also, ethical approval was gained from the local research ethics committee. A nurse from the unit accessed the database held by the oncology unit and printed a list of all children who had been diagnosed with cancer between November 1999 and November 2001. It was ensured that those children who had died were removed from the list. All children who were alive between the age of 5 and 18 diagnosed with cancer were then selected, giving a potential sample of 96 children meeting the inclusion criteria. Questionnaires were then mailed to the parents of all these children together with an introductory letter explaining the aims of the study and including a pre-paid self-addressed envelope, asking them to volunteer their participation in the study. Parents were assured that all information provided would be strictly confidential. A pilot study was carried out with four parents who were not part of the final sample, resulting in minor adjustments to the questionnaire.

## Data analysis

Data were analysed using the SPSS computer programme. Descriptive statistics were used to summarise the study variables. Spearman's rho correlations were also calculated to identify any associations between the study's variables in relation to the use of CAM. The information that was generated from the qualitative comments was analysed by simple content analysis.

## Results

### Demographic characteristics of the parents and children

Of the 96 questionnaires sent out to parents of children with cancer, 49 were received back, giving a response rate of 51%. In the majority of cases, the respondent was the mother (91.8%). The average age of the respondents was 38.5 years ( $SD = 4.63$ , range = 28–48). Ninety-eight per cent were white and the majority held professional occupations.

Five (10.2%) were teachers, 10.2% worked in healthcare, 10.2% in office work, 8.2% held managerial jobs, 4.1% worked in banking and 2% in media. Twelve (24.2%) of the respondents were housewives and 10 (20.4%) parents were labourers (Table 1).

The children had all received or were receiving conventional treatment for their cancer. Twenty-seven (55.1%) were boys and 22 girls. The youngest child was 5 years old and the oldest one was 17 (mean = 10.6 years,  $SD = 4.21$ ). The most common types of cancer were leukaemia (44.9%), brain tumours (20.4%), sarcomas (16.3) and solid tumours (Wilm's, parotid gland) (8.2%). On average, children were about 27.7 ( $SD = 10.11$ ) months post their cancer diagnosis and the average time since their treatment was 14.7 months ( $SD = 10.26$ ). The majority (40.8%) had or were

**Table 1** Characteristics of parents and their children ( $n = 49$ ).

	N	(%)
<i>Gender of parent</i>		
Male	4	8.2
Female	45	91.8
<i>Relation with child</i>		
Mother	45	91.8
Father	4	8.2
<i>Occupation</i>		
Housewives	12	24.5
Professionals	21	44.9
Labourers	10	20.4
Self-employed	2	4.1
Unemployed	2	4.1
Student	1	2.0
<i>Ethnicity</i>		
White	48	98
Black	1	2
<i>Gender of child</i>		
Boy	27	55.1
Girl	22	44.9
<i>Diagnosis</i>		
Leukaemia	22	44.9
Brain tumour	10	20.4
Sarcoma	8	16.3
Solid tumours (Wilm's, parotid gland)	4	8.2
Other	5	10.2
<i>Treatment</i>		
Chemotherapy	20	40.8
Chemotherapy & radiotherapy surgery	13	26.5
Chemotherapy & surgery	5	10.2
Radiotherapy & surgery	5	10.2
Surgery	4	8.2
Chemotherapy & radiotherapy	2	4.1

receiving chemotherapy as part of their treatment for cancer, followed by a combination of chemotherapy, radiotherapy and surgery (26.5%) (Table 1).

### Use of complementary and alternative therapies

Of the 49 parents who completed the questionnaire 16 (32.7%) had used or were using some form of complementary and alternative therapy to help their child. Of the children who had used CAM, most had used more than one therapy. Table 2 shows the types of CAM therapies used and the parental perception of effectiveness. The most commonly reported therapies were multivitamins (56.3%), aromatherapy massage (50%) and the use of diets/dietary supplements (37.5%). However, if the use of aromatherapy massage and aromatherapy are considered together they make the most commonly used therapy (68.8%). The questionnaire asked parents to rate their chosen therapy on a scale of 1–10 in relation to how much they felt their child was helped. The three most common CAM therapies used were largely viewed as being effective in relation to helping the child, each given a rating of between 6 and 8. Out of those parents who used CAM for their children, 15 (93.8%) said that they would recommend their chosen therapy to other parents in the same situation as themselves. The majority of parents used their chosen CAM on a daily basis (62.5%), while others used them frequently throughout the week (25%) and some used

**Table 2** Types of CAM used.

Types of CAM used	N = 16	%	Perceived effectiveness × (SD)
Multivitamins	9	56.3	6.71 (1.7)
Aromatherapy massage	8	50	8.71 (0.95)
Diets	6	37.5	7.17 (0.98)
Music as therapy	4	25	7.75 (3.3)
Aromatherapy	3	18.8	8 (3.46)
Massage	3	18.8	9 (1.73)
Herbal medicine	2	12.5	1
Faith healing	2	12.5	8 (1.4)
Homeopathy	1	6.3	1
Megavitamins	1	6.3	1
Vegetable juices	1	6.3	10
Healing	1	6.3	8
Alexander Technique	1	6.3	10
Humour/laughter	1	6.3	8
Sports/exercises	1	6.3	8

**Table 3** Reasons for use of CAM (n = 16).

Factor	N	%
To use every possible option in healthcare	13	81.3
To improve my child's general health	12	75
Helps to relax my child	9	56.3
Decreases my child's anxiety/stress	8	50
To reduce side effects experienced from treatment	8	50
Recommended by somebody	7	43.8
Effective in treating pain	6	37.5
Improve my child's immune function	6	37.5
To help prevent recurrence of cancer	6	37.5
To improve child's appetite/digestion	4	25
Hope to be cured without side effects	2	12.5
Disappointed with the treatment my child is receiving	1	6.3
To help wound healing	1	6.3
To stimulate senses, improve balance and posture	1	6.3

them less often, either once a week (6.3%) or monthly (6.3%).

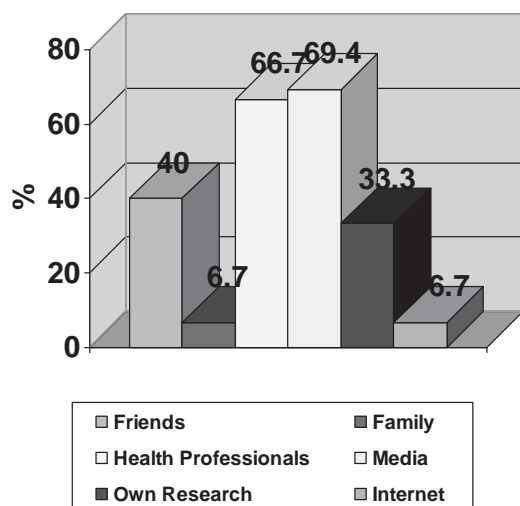
### Reasons for the use of CAM

Table 3 shows parental reasons for using complementary/alternative therapies. The majority of parents reported more than one reason for using CAM. The most commonly cited reasons for parents choosing CAM were to use every possible option in healthcare (81.3%), followed by to improve their child's general health (75%) and to decrease their child's stress and anxiety (50%).

### Sources of information about CAM

Figure 1 shows where parents obtained information about complementary therapies. Most parents received information from more than one source. The most common source of information was the media (69.4%). Ten (66.7%) parents stated that health care professionals provided some information about CAM. Six parents identified friends as the source of information about CAM therapies and five (33.3%) their own research. Few parents received information about complementary therapies from family and the Internet.





**Figure 1** Sources of information about CAM (in percentages).

## Correlations

A significant correlation was found between the frequency of CAM use and the time since the child was diagnosed with cancer ( $r_s = 0.66$ ,  $P = 0.006$ ) whereby the longer the time since diagnosis, the more CAM was used. A correlation was also found between the perceived benefit of using aromatherapy massage and decreases in the child's anxiety/stress ( $r_s = 0.75$ ,  $P < 0.001$ ). A moderate correlation was also identified between the use of aromatherapy massage and the perceived benefit of helping the child to relax ( $r_s = 0.88$ ,  $P = 0.004$ ) or the perception of being effective in treating pain ( $r_s = 0.62$ ,  $P = 0.01$ ). A significant correlation was shown between using diets and the perception of improving the child's immune function ( $r_s = 0.73$ ,  $P < 0.001$ ) as well as with using multivitamins ( $r_s = 0.68$ ,  $P = 0.004$ ). There were no associations between use of CAM and any of the parents' or children's sociodemographic characteristics.

## Qualitative comments

### Reasons for not using CAM

Some of the comments made by parents provided valuable insight as to why parents were not using CAM for their children. Four categories were identified, including that CAM was not necessary ( $n = 8$ ), they were unaware of CAM ( $n = 5$ ), CAM was not offered to them ( $n = 12$ ), and lack of information on CAM ( $n = 2$ ).

Many parents did not feel that there was any need to use complementary/alternative therapies for their child with cancer, many were happy with their child's conventional treatment and thought that their child was doing well. Some of the comments given by parents are presented below:

Not felt the need.

My daughter didn't really feel she needed any other treatment. We would try them in the future if appropriate.

One parent did not want CAM to interfere with the child's treatment and placed confidence in medical staff:

I leave it to the professional judgement of the doctors.

It was also evident from some of the responses that many parents were not aware of any therapies that were available other than conventional treatment to help their child with cancer. As a consequence they did not use them:

Never knew it was an option or of use.

Unaware of any others (treatments).

I wasn't aware at the time that any of these (CAM therapies) were used on children with cancer. We agreed to the conventional treatment and have tried to supplement it with healthy eating and sufficient exercise where possible.

Some parents indicated that their reason for their non-use of CAM was because they had not been offered or suggested by medical staff. One parent stated that if it had been offered CAM he/she might have considered it as an option:

This was not discussed or offered at the time by medical staff. If complementary/alternative therapies had been offered, my child said that he would have been interested.

We have not been offered them.

As well as stating that medical staff did not suggest the use of any CAM, one parent also thought that their child's conventional treatment was enough for her to cope with, without causing more stress by introducing more therapies:

Nothing was suggested by the medical team, also my daughter has coped very well with the treatment and I wouldn't have wanted to cause her any more anxiety by subjecting her to more treatments than were necessary.

Some parents felt that there was a general lack of information available about CAM which made it

difficult for them to be able to make a decision about what CAM they should/could be using for their child:

I don't have information on any other therapies.

Not enough information—difficult to obtain it.

### Perceived benefits of using CAM

The questionnaire also asked parents to indicate what they felt their child had gained from using their chosen CAM. Three categories were developed based on their comments, including increased confidence ( $n = 2$ ), pain relief ( $n = 6$ ) and relaxation ( $n = 5$ ).

A few parents felt that their child had gained confidence in different ways by using their specified therapy(s).

Confidence (faith healing and healing).

Fitness/confidence and a sense of being loved (aromatherapy massage, multivitamins and music as therapy).

Many parents also felt that by using CAM, it helped to ease their child's pain and discomfort from treatment:

It helped relieve significant pain and discomfort during treatment (aromatherapy, multivitamins, mental imagery and music as therapy).

It helped take his mind off side effects and pain to relax and sleep (aromatherapy, multivitamins, mental imagery and music as therapy).

Less pain, more comfort (aromatherapy, multivitamins).

My son used to get bad foot and leg pains which is a side effect of one of the chemos'. Massage with aromatherapy oils helped tremendously and I would recommend it to anyone.

Many parents further felt that by using CAM, it helped their child to relax, as the following comments indicate:

Aromatherapy massage relaxed and distracted her.

More relaxed, less frightened, less apprehensive, not so depressed after treatment (aromatherapy massage, relaxation exercises, music as therapy).

...During and after treatment used massage and music to relax/soothe. Was fortunate to be treated to aromatherapy massage twice in hospital, which was wonderful, especially during cramp pains. Music was also brilliant (and still is) for releasing pent up emotions and dancing.

Other comments that parents made in relation to their use of CAM for their child, were categorised into three main areas: uncertainty ( $n = 3$ ), provision of and access to information about CAM ( $n = 4$ ), and CAM as an additional help for their child ( $n = 5$ ).

It was evident from one of the comments given by one parent that she had often thought about and was interested in using CAM therapies for her child but was unsure as to which therapies would be effective. Additionally, this parent had concerns as to whether CAM would interfere with their child's conventional treatment and whether they would receive approval from doctors.

I would really like to use alternative medicine but didn't know if it would interfere with chemotherapy and if the doctors would approve.

We do not know what would be suitable to use for our daughter.

Many parents identified the need for better quality and accessible information to be made available about CAM therapies whether they used them or not, so that they may have more of an idea as to what might actually be beneficial. In addition, some parents commented on how it was difficult to determine what therapies were reliable and many felt that doctors/nursing staff should offer and discuss complementary therapies with parents so that they are able to make informed decisions. The following comments highlight this:

We have since discovered that some alternative therapy is available at the hospital but it is not really accessible and you are not offered it unless things get really bad.

...I think that complementary/alternative therapies should be discussed at the onset of the child's treatment so parents realise that this can be used as well as chemotherapy etc. My son was a few months into his treatment before I learnt about aromatherapy and massage. I think the ward should have some literature on alternative therapies and complementary therapies for parents to look at. I don't think enough is done to advise parents that these therapies can be very beneficial to their child.

One parent also thought that if she had been informed of CAM, a sense of control would have been achieved on her part in relation to her child's treatment:

I am very interested in the other therapies but had no knowledge about this, nor did I have the 'energy' to find out about them i.e. whilst dealing with my child's illness. However, had there been someone available to provide information/teach these methods, this would

have been ideal. I feel that this would have helped me to take back some control regarding my child's treatment.

### An additional help

Parents felt that by using complementary/alternative therapies, they were providing an additional way of helping their child to get through their cancer/treatment. Some parents believed that the use of CAM helped themselves, as parents, to feel as though they were doing everything possible to aid their child's recovery, and believed that CAM positively enhanced their child's recovery:

I believe there to be in both adults and children, both a physical and psychological side to recovery and using various methods of 'treatment' can only help this process providing they address both aspects and are complementary. Children are very literal and when they see/feel that parents and friends are pulling for them, it will enhance their recovery tremendously.

...Not only did the aromatherapy, music, massage and multivitamins improve my daughters well being during treatment for neuroblastoma but also helped ourselves knowing that her pain and discomfort had been reduced.

One parent explained how one particular type of CAM, that of the Alexander Technique remarkably improved their child's condition following other treatments being unsuccessful:

My daughter's head dropped to one side after treatment. Physio's/OT's (Occupational Therapists) said they could do nothing, the ophthalmologist said she needed an operation on her eyes. I took her to an Alexander teacher who corrected the problem in 3 weeks by 'retraining the brain'. I feel very strongly that conventional rehabilitation is rigid, inflexible and unimaginative. I don't believe in faith healing or anything weird and way out but I do believe there is much to be gained from 'thinking outside the box'.

### Discussion

A third of children were using some form of CAM for their cancer. This is in agreement with much of the recent literature (Fernandez et al., 1998; Grootenhuis et al., 1998; Bold and Leis, 2001). The sample represented parents using CAM for their children alongside their child's conventional treatment. This finding highlights how parents using CAM clearly saw these treatments as being 'adjuncts' to their child's conventional treatment for cancer and were not inclined to completely avoid the usual medical treatment. Furthermore, the fact that many

children incorporated the use of CAM on a daily basis highlights how CAM is seen as being part of the child's overall treatment regimen. Other researchers have also confirmed the fact that CAM is generally used alongside medical treatment by children and adults, rather than as a replacement for it (Downer et al., 1994; Sawyer et al., 1994; Cassileth and Chapman, 1996; Fernandez et al., 1998; Bold and Leis, 2000).

The most commonly used CAM was that of aromatherapy massage and aromatherapy. It has been suggested in the literature that aromatherapy and massage, in addition to other therapies have a place in the supportive care of cancer patients (Cawthorn and Carter, 2000), being one of the complementary therapies most commonly provided in UK cancer services. It is perceived as positive and beneficial by cancer patients (Corner et al., 1995; Wilkinson, 1996) and as a useful technique that can be used as an adjunct to conventional treatment, having stress reducing benefits (Cassileth and Chapman, 1996). Other existing research has suggested a short-term anxiolytic effect or an increase in quality of life (Corner et al., 1995; Kite et al., 1998; Wilkinson et al., 1999). Benefits were also reported by the parents when using aromatherapy for their child. This is in agreement with other studies where use of aromatherapy massage was associated with improvements in pain (Corner et al., 1995), significant improvements in physical, psychological and quality of life scores (Wilkinson et al., 1999) and significant improvements in mean anxiety and depression (Kite et al., 1998). This highlights the benefits that the use of CAM, particularly aromatherapy massage, can provide to children experiencing treatment for cancer. If their pain is reduced, they are more relaxed and less frightened, they are more likely to be able to cope with their treatment and the stress that having cancer imposes on them.

The use of aromatherapy massage may also have been particularly common due to the fact that this service was available at the hospital, which may have made parents more aware and interested in trying this particular therapy for their child. The fact that aromatherapy massage was not evident in many of the paediatric oncology studies in this area may be due to aromatherapy massage not being as easily accessible as it was in this study (Sawyer et al., 1994; Grootenhuis et al., 1998; Kelly et al., 2000; Bold and Leis, 2001).

Parents received information about CAM from a range of sources, the main source being the media, followed by healthcare professionals and friends. This contrasts with literature whereby parents have heavily relied in the past on information received



by word of mouth recommendation (Grootenhuis et al., 1994; Simpson and Roman, 2001) and through friends and family rather than from media reports (Begbie et al., 1996). These differences may reflect a time effect such as the increasing popularity of CAM that has occurred since these studies were carried out, which has seen the mass media discussing the use of CAM with increasing interest. As a result, it is not surprising that parents are more likely to have learnt about CAM through this medium as opposed to word of mouth recommendation in today's society. Also among those parents who were users of CAM, the majority were housewives and professionals. This may have increased the likelihood of them being exposed to numerous sources of information, which in turn may have prompted their interest in CAM.

Most parents who used some form of CAM for their children were satisfied with their chosen therapy in relation to the benefits it provided for their child and the majority of parents reported that they would recommend their chosen therapy to other parents in the same position as themselves. Parental motives appear to reflect the content of the literature relating to the use of CAM among paediatric oncology patients (Sawyer et al., 1994; Fernandez et al., 1998; Kelly et al., 2000; Bold and Leis, 2001).

Many parents in this study felt that by using CAM, their child's confidence had increased, particularly those that identified using faith healing, healing, aromatherapy massage and music as therapy. The benefit of increasing 'confidence' has not been reported as such by other studies. However, other cancer patients have reported feeling emotionally stronger, more able to cope with the demands of the illness and more optimistic and hopeful about the future by using CAM (Downer et al., 1994). The increased confidence reported in this study may also be due to the relaxing nature of the therapies used, which helped to improve the child's overall well being and enable them to keep their hopes alive for a positive outcome.

One of the major perceived benefits identified by parents for using CAM for their child was helping to ease and relieve significant pain and discomfort experienced by their child, both during and after their treatment, particularly chemotherapy. This has also been identified in other paediatric oncology studies (Fernandez et al., 1998; Bold and Leis, 2001; Sawyer et al., 1994). The use of CAM was particularly recognised as being helpful in taking their child's mind off the side effects of treatment, such as pain, which in turn had helped their child to relax, helping them to sleep better as a result. Barakat et al. (1997) highlighted how the treat-

ment that children receive for their cancer is generally more aggressive than it is for the treatment of adult cancers. This is a factor that is likely to have encouraged parents to seek other options such as CAM for their children, which are effective in helping them to cope with the side effects of treatment.

Some parents were using CAM to support their child's treatment as indicated in the findings by Bold and Leis (2001). One parent in particular expressed their viewpoint towards conventional rehabilitation and reasoning behind why they had chosen to use CAM. It was felt that conventional rehabilitation was 'rigid, inflexible and unimaginative' and they believed that there was much to be gained from 'thinking outside the box'. This highlights how there is perhaps much more to the treatment of cancer than just conventional medical treatment. It maybe that CAM has the potential to offer that 'added extra' to help the overall treatment process. Another parent reported the value that using CAM had both for their child and for themselves as parents, highlighting the indirect effect on the whole family. This particular parent felt that by using CAM, it had improved their daughter's well being whilst on treatment and had also helped themselves in knowing that they had helped to reduce their child's pain and discomfort (aromatherapy, music, massage and multivitamins).

The provision of information about CAM appeared to be an area that many parents thought required attention. Several parents expressed that there was not enough done in terms of informing and advising them about CAM and highlighted that it would be beneficial if more information was available on the oncology ward. This relates to other research studies which have reported parents having a lack of knowledge concerning CAM in addition to parents highlighting a need for better quality information (Fernandez et al., 1998; Bold and Leis, 2000). This demand for more information may be related to feelings of doubt on the part of parents regarding the efficacy, safety and possible interference of CAM with their child's medical treatment. The provision of more information may be a way of reassuring those parents who are interested in using some forms of CAM for their children that it is safe to do so.

The findings however should be viewed in light of the study's limitations. One of the main limitations of this study relates to the relatively small sample obtained, which makes it difficult to generalise the results. A larger sample from a multicentre study is necessary in the future. Further, literature indicates that over time major changes take place in whether patients with cancer use CAM and in the

number and types of CAM used (Verhoef et al., 1999; Risberg et al., 1998), and the current cross-sectional design does not allow for such information to be obtained. Furthermore, it was unclear whether parents had accepted their child's illness and how well they were coping with it, and so parents may have been too distressed to complete the questionnaire, decreasing the response rate and skewing somewhat the results.

### Implications for practice

It is likely that both nurses and doctors will encounter parents of children who are either using or are keen to use CAM in conjunction with their conventional treatment as the use of such therapies is receiving increasing interest in today's society (Richardson, 2001). Parents will often turn to health professionals seeking information when making decisions about the use of CAM and will often be asked about their opinions regarding certain therapies. Therefore, as the attitudes and beliefs of health professionals are likely to influence the response to the patient's inquiries (Fitch et al., 1999), health professionals need more information about the various forms of CAM available. It is evident from the findings of this study that a great deal more needs to be done in terms of educating health professionals about CAM. Health professionals need to receive increased training in this area so that they are prepared and able to answer the parents' questions and are able to openly discuss and share the information when approached by those parents who are interested in their use (Richardson, 2001).

The use of CAM could be discussed with parents at the start of treatment. Furthermore, more accessible, reliable information, which is of high quality, would be a useful resource to have available for parents at the ward level. This would increase parental knowledge and awareness about CAM and would give them the opportunity to at least be able to consider such use for helping their child during treatment.

### Conclusion

The findings suggest that the use of CAM is commonly used by children with cancer who have/are receiving treatment. The fact that the use of CAM has been reported as having both positive and beneficial effects for children with cancer suggests that its use should perhaps be an integral part of the treatment that children receive

for their cancer. With the understandable anxiety and stress that having a child with cancer creates, it is not surprising that this study has highlighted how parents are motivated to use CAM which have the potential to provide additional assistance, hope and reassurance for their children whilst on treatment. It is essential that medical staff respect parents' decisions and interest in using CAM as their way of feeling involved in their child's treatment and providing the best quality care and support for their children.

An integral part of the children's care should be the provision of information and education for both parents and health professionals to ensure that all children have the opportunity to at least consider using CAM. For paediatric oncology patients to be deprived of CAM due to fear or misinformation, may mean that the needs of such children are not fully addressed. If the findings of this study are given some consideration in the paediatric oncology setting, it may help to review and improve the way children are treated and cared for in the future.

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