

Right: Aromatherapy is the use of essential oils, extracted from aromatic plants and flowers, for therapeutic effects. The scent of essential oils is conveyed by the olfactory nerve then to areas of the brain that can influence emotions and hormonal response



Complementary therapies in palliative care of children with cancer: a literature review

Families do not always disclose their use of complementary and alternative therapies for their children, as Jacqueline Scrace found in her review

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KEY WORDS

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Alternative therapies

The term complementary/alternative medicine (CAM) is used to refer to a diverse group of health-related therapies and disciplines which are not considered to be a part of mainstream medical care (House of Lords 2000). But CAM, such as aromatherapy and massage, can play an important role in relieving symptoms and, in turn, in improving quality of life. For parents of children with cancer, CAM enables them to help alleviate some of their child's discomfort during a time when they often express feelings of helplessness.

However, nurses do not always acknowledge such benefits and there is not always an infrastructure to support and promote the use of CAM in practice in hospital settings. This review aims to establish a greater understanding of how CAM could be used in palliative care to enhance a child's quality of life and to illustrate

how nurses might use this knowledge to improve the care they offer to the child and family.

The question addressed in the review is: How might CAM be used to improve the care we offer children with cancer during the palliative phase of their illness? A review of the research on the use of CAM in nursing practice is presented. Common themes emerging from the research are used to explore what CAM is being used by patients and their families as well as reasons for its use. Gaps in the research are identified and recommendations made for improving nursing practice.

The evidence

Ten research papers that explored the use of CAM in different areas of nursing were reviewed. A variety of research methods were used within both positivist and

naturalistic paradigms and the appropriate frameworks for analysis were used to guide the review.

It was expected that much of the research examining the use of CAM would be in areas other than paediatric nursing, and this turned out to be the case – only three of the ten papers related directly to paediatric cancer care (Grootenhuis *et al* 1998, Kemper 2001, Sawyer *et al* 1994). However, as most of the researchers considered issues of reliability, validity or trustworthiness, it was possible to consider how some of these findings might be applied to supporting the child and family during the palliative phase of cancer. It is recognised that although it may not always be possible to apply research findings directly to practice, there may be other aspects of the research that provide the ‘building blocks’ for developing new ways of thinking about the way palliative care for children is managed.

Following the analysis of the chosen papers it was possible to identify four major themes running through the literature. They are as follows:

1. Patients'/families' need for control

‘One of the primary cited reasons why individuals seek unconventional therapies, was their pursuit of control over the disease and what is happening to their lives’ (Fitch *et al* 1999).

Patients believe that if they can change their lifestyle in some way they may influence the outcome of their disease (Downer *et al* 1994). It is also suggested that parents of children receiving complementary therapies are more motivated to find a cure for their child (Armishaw and Grant 1999). Individuals want to make sure that they have ‘covered all the options’ and make sure they have ‘the best shot at having the best chances of survival’ (Fitch *et al* 1999).

Families of children who had cancer that had relapsed used alternative treatment more often. At this time it could be said that families are more likely to be desperate for a cure for their child. The use of alternative treatment becomes appealing when confronted with long-term feelings of uncertainty. Parents may believe that they can exert some control in an otherwise uncontrollable situation (Downer *et al* 1994, Grootenhuis *et al* 1998, Fitch *et al* 1999). Alternatively, it can be argued that as a result of social change people feel more able to take control of their wellbeing and move away from the dependence on experts toward more personal

participation, choice, self-reliance and re-assertion of individuality (Chadwick 1999).

2. The need for a more collaborative approach

The need for a more collaborative approach between health professionals and the patient and family is a big issue when exploring the use of CAM. Sawyer *et al* (1994) discovered that fewer than half of the parents of children using alternative therapies had informed their children’s doctors that they were using such therapies.

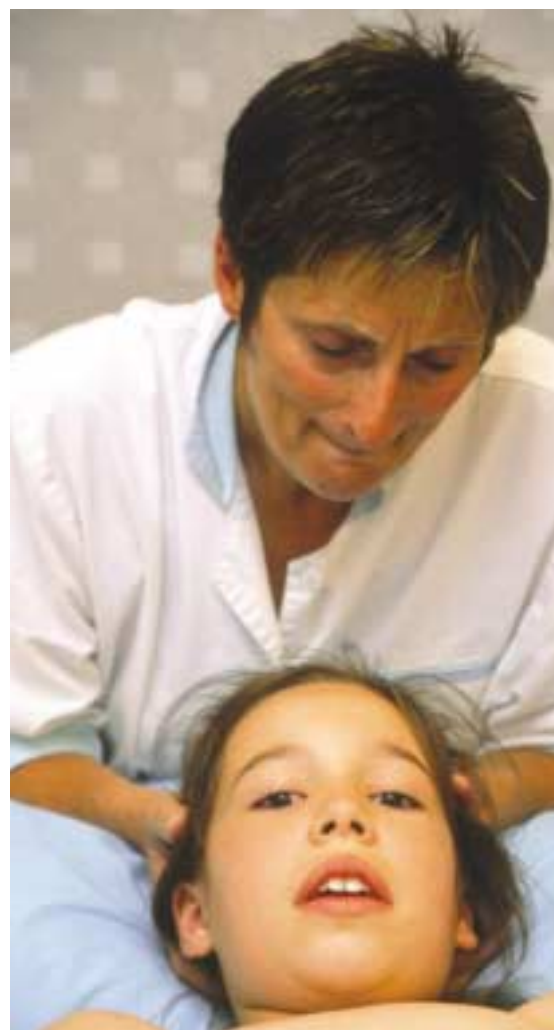
Reasons why patients and their families may not inform health professionals have been identified as:

- disappointment in medical care and placing hope in other possibilities
- a matter of personal choice, so therefore no need to discuss with children’s doctors
- the belief that the children’s doctors would be cynical and unsupportive
- fear of how the topic will be received, and
- physician unawareness of therapies serving as a barrier (Fitch *et al* 1999, Grootenhuis *et al* 1998, Sawyer *et al* 1994).

It can be argued that if healthcare professionals do not communicate with patients and their families it may result in two treatment protocols: one that is monitored and one that is not, and as a consequence there is no awareness of how they interact (Fitch *et al* 1999). It is possible that if the therapies adversely affect a child, the true cause of the child’s problems may not be recognised (Sawyer *et al* 1994).

The ideal practice would be to enquire about the use of CAM for every child that is seen. This should be done in such a manner that does not denigrate the parents’ genuine efforts to seek help for their sick children.

Below: Osteopathy is an established, recognised system of diagnosis and treatment which lays its main emphasis on the structural and functional integrity of the body. It is distinctive in that it recognises that much of the pain and disability we suffer stems from abnormalities in the function of the body structure as well as damage caused to it by disease



This is an area of particular importance when '...conventional medicine does not always hold an immediate cure' (Armishaw and Grant 1999).

3. CAM as an addition to orthodox medicine

Many patients use complementary treatment as an adjunct to orthodox medicine rather than an alternative. Armishaw and Grant (1999) found that during the acute illness children receiving complementary treatment visited their GP as frequently as those children treated exclusively with orthodox medicine. Most respondents in Downer *et al*'s (1994) study of adult cancer patients expressed satisfaction with their conventional treatment.

4. The role of the nurse

Contrary to expectations, Chadwick (1999) discovered that the main reason nurses gave for using complementary therapies in practice was role expansion. Issues highlighted by these nurses included the increased scope of practice, independence of judgement, decision making and action. Furthermore, it was felt that CAM should be an integral part of nursing practice.

Nurses were keen to actively learn what therapies patients were using and be able to talk to them about such therapies. It was also felt



Traditionally, acupuncture is an holistic approach to the management of disease as well as the maintenance of health

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or had offered some form of CAM despite the fact that they did not have permission to practise these therapies in their hospitals. Rankin-Box's study revealed that a number of employing organisations did have policies covering the practice of complementary therapies but half of participants stated that there were no defined standards in place. Furthermore, 62 per cent of

'When the conspiracy of silence exists, it just feeds the anxiety and the loneliness of the cancer experience'

that there ought to be a way of working these therapies into the system of care and offering some therapies as standard care. Suggestions were made for mixed educational programmes in which healthcare professionals could learn from each other and respect each other's contribution (Fitch *et al* 1999, Rankin-Box 1997). The approval of the NHS trust or other employer would need to be obtained before a practitioner qualified to practise a complementary therapy could offer that therapy to patients as part of their care (Dimond 1997).

Studies by Rankin-Box (1997) and Fitch *et al* (1999) discovered that some nurses were using

subjects indicated that there were no formal mechanisms with which to evaluate the use of complementary therapies in care (Rankin-Box 1997).

These findings were supported by Fitch *et al* (1999) who reported that one of the barriers to general implementation was a lack of hospital policy and lethargic management.

Implications for practice

At the outset it was decided to include research from outside of the UK as the use of CAM was said to be low here compared to other countries. However, half of the papers studied were based

on research conducted in the UK. While it is recognised that differences do exist between countries in terms of the way health care is accessed and ethnic and cultural differences exist, the themes that emerged from the literature were very similar.

Available research findings suggest that nurses are keen to learn more about the use of CAM. One way to begin integrating its use in nursing practice might be to provide better opportunities for practitioners who express an interest to improve their knowledge base and develop the necessary skills to implement therapies. However, it is essential that nurses maintain this competence through regular updating under the UKCC's guidelines for post registration education and practice (Dimond 1997), as they would any other aspect of their practice.

There will always be a proportion of cancer patients and their families who are attracted to alternative and complementary therapies. With better knowledge and understanding health professionals can assist them to make informed choices about such therapies (Sawyer *et al* 1994). One of the most significant findings of this review is that an important reason for choosing to use CAM stems from the patients'/families' need for control. As the studies reported, alternative treatments gave the patients/families a degree of hope in that they may be able to influence the outcome of their disease and achieve some control over what was happening in their lives.

Multidisciplinary collaboration and communication are essential if CAM is to play a more significant role in symptom control and pain management during the palliative phase of illness. Team discussions regarding the use of CAM would give health professionals the opportunity to meet and share knowledge and experiences, thus facilitating better communication and open discussion about alternative treatments.

Nurses have a key role in facilitating this multidisciplinary approach as they are often the first people that the child and family feel comfortable to approach. Besides establishing

'Enquiring about the use of CAM in all children that are seen is recommended as best practice for doctors'

effective relationships with the child and family in order to offer support, nurses need to be aware of the different views and beliefs that families might have with regard to the use of alternative treatments. They need to try to understand these attitudes within the context of coping with the illness (Grootenhuis *et al* 1998).

Discussion

Family-centred care involves a two-way process between the nurse and the child and family to construct a mutually agreed plan of care, with each participant being of equal value (Smith 1995). However, the findings of this review suggest that parents often perceive health professionals as being unsupportive in their choice of treatment. Although many patients/families expressed satisfaction with conventional treatment and only pursue the use of alternative treatment if used in addition to orthodox medicine, they seldom disclose the use of CAM.

The implications of such secrecy can be very serious. For instance, some alternative therapies may interfere with orthodox treatment and seeking alternative treatment for children may delay the use of orthodox medicine for those with a potentially severe illness (Armishaw and Grant 1999, Sawyer 1994). 'When the conspiracy of silence exists, it just feeds the anxiety and the loneliness of the cancer experience' (Fitch *et al* 1999).

If parents are not willing to disclose the use of CAM to the doctors, then the role of the nurse could be to negotiate between the child and family and the doctors. An open discussion may help alternative treatment to become more accepted (Grootenhuis 1998).

CAM practice cannot be implemented without health professionals having adequate knowledge and training, together with appropriate supporting standards and policies in place within an organisation. Development of guidelines and protocols about the use of CAM in managing side effects or pain during the palliative phase of cancer might also be a step forward in helping parents to feel supported in their choice of treatment.

If parents express an interest in the use of CAM for their child, it may be beneficial for the nurse to introduce a specialist practitioner in CAM to team meetings where treatment options for a child in the palliative phase of cancer are discussed.

Enquiring about the use of CAM in all children that are seen is recommended as best practice for doctors (Armishaw and Grant 1999, Kemper 2001). Alterations to admission documentation to include the child and family's expectations of treatment and whether they express any interest in the use of CAM would improve communication and the support offered. Such changes are only possible where

there is a supporting infrastructure within the workplace.

Conclusion

As this review demonstrates, there is a need for more research to explore the use of CAM, not only in palliative care of children with cancer but also in other areas of children's nursing. Potential research areas might be the use of CAM in managing the side effects of chemotherapy or post-operative pain control in children.

It is said that the use of CAM is increasing, particularly for the sickest children (Kemper 2001). Child health nurses need to be aware of the different attitudes that exist towards CAM and be able to offer appropriate guidance and support to parents if they feel it necessary to explore alternative treatments during their child's illness.

When parents turn to new therapies in the hope that they will be beneficial to their child, nurses need to be able to ensure that necessary information to make an informed choice is available. This applies as much to alternative therapies as it does to conventional therapies and requires nurses to have an awareness of attitudes to CAM, knowledge of the different therapies and the ability to establish effective relationships with the child and family and the multidisciplinary team.

Nurses caring for the child with cancer who is entering the palliative phase are in a unique position to ensure that the multidisciplinary approach to the care of the child takes into account the strong desire of parents to continue to provide hope and support to their child (Sawyer *et al* 1994) **PN**

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