PATIENTS' PERCEPTIONS OF COMPLEMENTARY AND ALTERNATIVE MEDICINE

Vivienne O'Callaghan
Cancer Council NSW, New South Wales.
Email: vivienneoc@nswcc.org.au

Abstract

Patients' perceptions of complementary and alternative medicine are not well studied. This review highlights attitudes towards complementary and alternative medicine, particularly for cancer patients. In general, the longer the time since a cancer diagnosis, the more likely it is that someone may use complementary and alternative medicine. In addition, women of a younger age with a higher education are more likely to use complementary and alternative medicine. Most commonly, complementary and alternative medicine is used to treat a range of physical and emotional problems relating to cancer, and only rarely as a means to cure the cancer itself. Dietary supplements, dietary changes and meditation are the most commonly used therapies. Many people perceive that these – and other complementary and alternative medicines – are beneficial for both physical and emotional reasons. However, not all people gain their desired outcomes from using complementary and alternative medicine. There are few reports of negative effects, but these are factors in some people not using or ceasing complementary and alternative medicine. Others do not use complementary and alternative medicines because of disbelief or due to concerns about complementary and alternative medicine benefits or safety. Doctors are not always consulted about complementary and alternative medicine use, but many people hope their doctors are supportive of it.

Understanding patients' perceptions of complementary and alternative medicine (CAM), particularly with regards to cancer care, is a developing area of research. Although numerous studies document the increasing use of CAM in developed countries particularly for cancer,[1,2,3] fewer studies have dealt directly with peoples' perceptions of CAM.[4] Understanding these attitudes should permit greater insight into the reasons for increasing CAM use, and improved understanding of the breadth of patients' needs.

This review considered studies from Australia, New Zealand, North America and the United Kingdom. Because of differing populations, lifestyles and culture, studies from non-English speaking countries, developing countries, Asia and the Middle East were excluded.

Studies were reviewed for information relating directly to predictors of use and general attitudes towards CAM. Additional related aspects considered in this review, and described in Humpel and Jones,[4] are: types and timing of CAM use, reasons for not using or ceasing use of CAM, motivations for CAM use, perceived positive and negative effects from CAM, sources of information on CAM, and communication with doctors.

Predictors of use and general attitudes towards CAM

People who used CAM before a diagnosis are more likely to use CAM after their diagnosis,[5,6] but the biggest predictors of use are being female, younger and tertiary educated.[6,7,8,9]

Shorofi and Arbon claim women are more likely than men to have a positive attitude towards CAM.[8] Other studies conclude women are 1.9 times more likely than men to use CAM.[9,10] Hedderson et al found that about 80% of women and 60% of men used at least one CAM, and suggested "it may be considered more socially acceptable for women to seek help".[10] But men were more likely to use CAM when their symptom distress scores were higher.

The literature appears to show that the longer the time since diagnosis, the greater the likelihood of CAM use.[5,11] This increase may be due to the need to deal with unwanted side-effects or a desire to seek natural health care.[11] Changed beliefs about health, illness and medical care may lead to CAM use.[5,11] Beyond five years since diagnosis, however, CAM use seems to decline, except in patients with poor prognosis.[11]

In a review of public attitudes to natural medicine, Leach reported that regular CAM users were more likely to be dissatisfied with conventional practitioners than non-users,[1] and that over 40% of users turn to natural therapies because of a perceived failure of orthodox medicine to treat their health problems. O'Callaghan and Jordan,[7] in their survey of 'postmodern predictors' of CAM use, quote one study with a contrary finding: that although dissatisfaction with the doctor-patient relationship and having postmodern values of health are significant predictors, dissatisfaction with medical outcomes is not. O'Callaghan and Jordan conclude that holding postmodern values – such as rejection of authority, and feeling responsible for one's own health – predicts a positive attitude to CAM use.[7]

In Shorofi and Arbon's comprehensive study of CAM attitudes,[8] 46% of respondents had a positive attitude towards CAM, while only 10% had a negative attitude. In this study, patients rated their level of agreement to 18 statements about attitudes towards CAM and allopathic medicine. Examples include: 'CAM is an important aspect of my own family's health care' (36% agree, 25% disagree, 35% unsure) and 'conventional health care services are too impersonal' (27% agree, 44% disagree, 26% unsure).

All statements attracted large numbers of uncertain patients. Over 50% of respondents said that they were unsure about the following propositions:

- Surgical patients can be helped by CAM (41% agree, 5% disagree)
- Some forms of CAM work better than conventional treatment (35% agree, 8% disagree)
- CAM therapies are completely safe (28% agree, 14% disagree)
- Positive effects of CAM are due to placebo effect (12% agree, 24% disagree).

The lowest rates of uncertainty were reported for the following propositions:

- Both mind and body must be treated for the patient to regain complete health (78% agree, 6% disagree, 14% unsure)
- Patients should have the right to choose between conventional treatments and CAM therapies (74% agree, 7% disagree, 17% unsure).

Types and timing of CAM use

Taking dietary supplements, making dietary changes and practising meditation were consistently the most common types of CAM used by cancer patients in a range of studies.[2,4-6,8,12-14] One study surveyed women at high risk for breast cancer, and out of 489 CAM users, 81% used dietary supplements, 51% used physical therapies and 44% used mind/body therapies.[15]

Other commonly cited CAMs (between about 10% and 40% of patients in a range of studies) include spirituality,[12,14] herbal medicine,[5,9,12,14] relaxation,[6,13,14] imagery,[5,12,14] massage and aromatherapy.[6,8,12,14,15] Acupressure, yoga, chiropractic,[4,8] and music therapy,[8] had relatively high usage, but were only cited in one or two studies.

Patients use CAM post cancer diagnosis, during treatment and during recovery. Humpel and Jones found that 13 of 19 patients started using CAM at the time of their diagnosis and six during or following treatment.[4] Evans et al reported that men using CAM tended to do so at different points in their life, depending on health needs, as well as at different stages of their diagnosis, treatment and recovery.[3] CAM use following conventional treatment was particularly important, as this time was "a trigger point for anxiety [and] conventional care may have little to offer at this time".[3]

Motivations for CAM use

Miller et al found that expectations for CAM use varied widely depending on the therapy being used.[5] In addition, the literature reports numerous reasons for CAM use across many studies. Most usually, people adopt CAM to:

- improve physical wellbeing[2-4,13]
- improve emotional wellbeing[2,3,13]
- reduce side-effects from conventional treatment [2-4,11,13,14,16]
- improve quality of life. [3,14,16, 17 -

Fewer numbers of people hope their CAM use will:

- prevent cancer from returning[2,4,11,14]
- assist in treating cancer [2,14]
- reduce cancer symptoms [2,14,16,17]
- boost the immune system. [2-4,11]

Other general reasons for using CAM include:

- having a sense of control [4,5,17-19]
- being more holistic/less toxic [3,4,19]
- feeling more hopeful[18]
- curing the cancer/better survival.[3-5,11,14,16,17,19]

Kremser et al concluded that women sought CAM as a means of coping holistically with the impact of breast cancer.[2] Most did not expect a cure, but hoped to manage the impact of the disease on their emotional and physical wellbeing. Other studies found that likely users had expectations that CAM would improve quality of life and symptoms, rather than cure cancer or prolong life.[14,19]

Salminem et al suggested that some people feel responsible for having cancer or their high level of cancer risk.[2] These patients are said to be more amenable to CAM use. Markovic et al calls this type of person a 'consequential user' of CAM.[11] Field et al found that women at high risk of developing breast cancer are also high users of CAM (55%), but for other reasons besides cancer prevention.[15] Only 6% used CAM specifically to prevent cancer. This result was unexpected and differs from similar studies.

A minority of people did hope CAM would cure cancer.[3-5,11,14,16,17,19] Markovic et al label these people 'exploratory users'.[11] These individuals are more likely to use radical treatments such as oxygen therapy or apricot kernels, or meditation, to try to cure their cancer.[11] Miller et al also found that small numbers of patients hoped for a cure (using meditation, diet, supplements, herbal medicine, shark cartilage, high-dose vitamin C, mental imagery, Gerson therapy and reiki).[5] The majority, however, used therapies to feel in control and to assist treatment.

Markovic et al suggest that 'Informed users' place equal merit in conventional medicine, but hope to

maximise their health outcomes by using CAM.[11] A finding in Sibbritt et al's study of elderly Australian women with cancer was that those who went to a CAM practitioner accessed conventional services as much as non-users of CAM.[20] This suggests that CAM users seek something that conventional health is not providing. One need possibly not being met through conventional care is a patient's desire to feel in control.[5]

Evans et al found that some men were dissatisfied with the process of conventional cancer care, rather than the treatment itself; this led to them using CAM alongside conventional treatment.[3] These men accepted and valued conventional treatment but used CAM for additional support. Many men also wanted a therapist with whom they could communicate well. They found this need met by CAM therapists rather than time poor oncologists.[3]

Reasons for not using or ceasing CAM

Most studies consider why patients use CAM rather than why they don't. The only non-user in Humpel and Jones' study identified herself as a non-believer, with there being no proof that CAM worked.[4]

Lack of knowledge is an important factor in non-use of CAM.[11,16] Markovic et al suggested that due to the rareness of gynaecological cancer, affected women's friends and family have no experience with the cancer and therefore aren't able to give advice or suggestions.[11] This tends to happen among many women with breast cancer.[2]

O'Connor and White found that out of 357 people, 202 were unlikely to have a consultation in the next two months.[21] Laziness, lack of availability and lack of knowledge about a therapist or CAM, were given as reasons for non-use of CAM. Seventy-seven people were unwilling to have a free CAM trial. These people were less likely to believe CAM would improve their health than those willing to have a trial.

Lack of knowledge about CAM and belief that CAM was ineffective meant that 38% and 16% of respondents respectively in Lewith et al's study did not use CAM.[16] Other factors limiting use were lack of availability (22%), concern about interactions between CAM and conventional treatment (20%), opposition from a doctor (10%), and concern CAM was harmful (9%).[16] Cost was also a barrier to use.[16,18] Markovic et al attributed low levels of CAM use to the majority of participants in that study being from a lower socioeconomic background.[11]

Perceived positive and negative effects from CAM

Only a few studies report on perceived outcomes from using CAM. Verhoef et al states that "the lack of appropriate outcome measures to assess the benefits of integrative health care has been identified repeatedly and continues to plague integrative health care research."[22] Patterson et al assessed whether a range of therapies improve wellbeing.[23] In this study, of those seeing CAM practitioners, 92% claimed their well being improved, mind/body therapies conferred improvement for 82%, dietary supplements 88% and herbs was 86%.

Miller et al found that 63% of patients felt CAM gave them psychological benefits and 41% physiological benefits.[5] A majority would recommend the treatment they had and use the same therapy again themselves. However, 29% thought CAM provided no benefit.

Salminem et al found that 25% of women reported no improvement from a change in diet.[12] However, 50% felt their condition had improved, while 25% were unsure. Harris et al's survey of 1034 people with cancer determined that 72% were satisfied with their CAM use, 25% were uncertain and 4% were dissatisfied.[6] A similar result was reported by Chrystal et al,[14] where 71% of patients thought CAM beneficial and 6% found CAM unhelpful.

Participants in Humpel and Jones' study revealed general responses to CAM use, such as having more energy, and feeling more positive and healthier.[4] Others were unsure if there were any benefits. Six patients (31%) reported some negative effects, including weight loss and a reaction to herbs. One patient stopped using herbs due to concern about cancer recurring; another stopped using CAM because of no perceived benefit.[4]

A participant in Verhoef et al's study reported an improvement in physical wellbeing, with massage or a natural health product most likely to cause these positive outcomes.[22] Some participants cited emotional improvements, including feelings of greater control, more optimism, reduced anxiety and greater resilience. Others believed that CAM helped them remain cancer free.

Sources of information on CAM

Kremser et al's study found that most women with breast cancer talked to their doctor (67%), their friends (67%), other women with breast cancer (61%) and family (54%).[2] Women using CAM for menopause mainly got information from friends, but the internet, books, magazines, colleagues and general practitioners were also used.[18] Other studies have put the rate of information coming from friends and family at about 30%.[4,17] CAM practitioners were also nominated frequently.[2,4]

The internet is a common (25%-30%) source of information,[2,4] although Wilkinson et al's study of men with prostate cancer did not find this (4%).[17] Magazines and newspapers are also influential, while television and radio are less so.[2]

Communication with doctors

Wilkinson et al reported that only 41% of men with prostate cancer had informed their oncologist of their CAM use, and older patients were less likely to discuss the topic.[17,20] A possible reason is that older people may fear their oncologist's disapproval.[20] One woman in Humpel and Jones' study admitted this.[4]

Richardson et al found that half of patients claimed they didn't discuss CAM because they weren't asked about it.[19] Similarly, Shorofi and Arbon reported that patients did not routinely discuss CAM with doctors.[8] The authors found that about 20% of CAM users would discuss CAM if they were asked.

Despite finding that 67% of women reported they had discussed CAM with their doctors, Kremser et al also found that many women felt that there was little opportunity for discussion of their CAM use with their doctors.[2] Salminem et al also found that patients wanted to talk about CAM with doctors, and Gollschewski et al concluded that the level of support from a general practitioner was a major influence in a woman's decision to take CAM for menopause.[12,18]

Some studies showed that people considered general practitioners to have a negative view of CAM.[4,18] Miller et al found, however, that doctors' support was perceived to be high for exercise, acupuncture, meditation, relaxation, hypnotherapy and use of antioxidants, but low for herbs and high-dose vitamin C.[5]

In a review of cancer patients' experiences using CAM, Smithson et al found that there was a desire for better integration of CAM and conventional medicine.[24] Moreover, patients didn't expect doctors to believe in the philosophy of CAM, but wanted their doctor's approval and to know that their CAM choices were reasonable and safe.

Conclusion

The literature shows that people's perspectives on CAM vary widely and that many people are uncertain about their own attitudes towards CAM and orthodox medicine. While the majority of people with cancer tend to use CAM to manage physical and emotional side-effects and improve quality of life, there are also a few people who use CAM in the hope that they will cure cancer or prolong their life. This finding, however, is rare. For many people, CAM seems to offer positive emotional outcomes, helping them feel more in control, increasing their optimism and improving their resilience. This suggests that CAM, for some people, addresses needs that are unmet by conventional health care. Conversely, not all people who try CAM find it beneficial. The literature suggests that while many people do talk to their doctors about CAM use, this rate would increase significantly if doctors initiated conversations and had an open approach about CAM.

References

1. Leach MJ. Public, nurse and medical practitioner attitude and practice of natural medicine. Complementary Therapies in Nursing and Midwifery. 2004;10:13-21.
2. Kremser T, Evans A, Moore A, Luxford K, Begbie S, Bensoussan A, et al. Use of complementary therapies by Australian women with breast cancer, The Breast. 2008;17:387-94.
3. Evans MA, Shaw ARG, Sharp DJ, Thompson EA, Falk S, Turton P, et al. Men with cancer: is their use of complementary and alternative medicine a response to needs unmet by conventional care? Eur J Cancer Care. 2007;16:517-25.
4. Humpel N, Jones SC. Gaining insight into the what, why and where of complementary and alternative medicine use by cancer patients and survivors. Eur J Cancer Care. 2006;15:362-8.
5. Miller M, Boyer MJ, Butow PN, Gattelari M, Dunn SM, Childs A. The use of unproven methods and treatment by cancer patients: frequency, expectations and cost. Support Care Cancer.1998;6:337-47
6. Harris P, Finlay I, Cook A, Thomas KJ, Hood K. Complementary and alternative medicine use by patients with cancer in Wales: a cross-sectional survey. Complementary Therapies in Medicine. 2003;11:249-53.
7. O'Callaghan FV, Jordan N. Postmodern values, attitudes and the use of complementary medicine. Complementary Therapies in Medicine. 2003;11:28-32.
8. Shorofi SA, Arbon P. Complementary and alternative medicine (CAM) among hospitalised patients: an Australian study. Complementary Therapies in Clinical Practice. 2010;16:86-91.
9. Girgis, A, Adams J, Sibbritt D. The use of complementary and alternative therapies by patients with cancer. Oncology Research. 2005;15:281-89.
10. Hedderson M, Patterson R, Neuhouser ML, Schwartz SM, Bowen DJ, Standish LJ, et al. Sex differences in motives for use of complementary and alternative medicine among cancer patients. Alternative Therapies. 2004;10(5):58-64.
11. Markovic M, Manderson L, Wray N, Quinn M. Complementary medicine use by Australian women with gynaecological cancer. Psychooncology. 2006;15:209-20.
12. Salminen E, Bishop M, Drummond R, Salminen S, Dietary attitudes and changes as well as use of supplements and complementary therapies by Australian and Finnish women following the diagnosis of breast cancer. Eur J Clin Nutr. 2004;58:137-44.
13. Seers HE, Gale N, Paterson C, Cooke HJ, Tuffrey V, Polley MJ. Individualised and complex experiences of integrative cancer support care: combining qualitative and quantitative data. Support Care Cancer. 2009;17:1159-67.
14. Chrystal K, Allan S, Forgeson G, Isaacs R. The use of complementary/alternative medicine by cancer patients in a New Zealand regional cancer treatment centre. New Zealand Medical Journal. 2003;116:1168.
15. Field, KM, Jenkins MA, Friedlander ML, McKinley JM, Price MA, Weideman P, et al. Predictors of the use of complementary and alternative medicine (CAM) by women at high risk for breast cancer. Eur J Cancer Care. 2009;45:551-60.
16. Lewith GT, Broomfield J, Prescott P. Complementary cancer care in Southampton: a survey of staff and patients. Complementary Therapies in Medicine. 2002;10:100-106.
17. Wilkinson, S, Gomella LG, Smith JA, Brawer MK, Dawson NA, Wajsman Z, Lanting D, Chodak, G. Attitudes and use of complementary medicine in men with prostate cancer. J Urol. 2002;168:2505-9.
18. Gollschewski S, Kitto S, Anderson D, Lyons-Wall P. Women's perceptions and beliefs about the use of complementary and alternative medicines during menopause. Complementary Therapies in Medicines. 2008;16:163-8.
19. Richardson MA, Masse LC, Nanny K, Sanders C. Discrepant views of oncologists and cancer patients on complementary/alternative medicine. Support Care Cancer. 2004;12:797-804.
20. Sibbritt, D, Adams J, Easthope G, Young A. Complementary and alternative medicine (CAM) use among elderly Australian women who have cancer. Support Care Cancer. 2003;11:548-50.
21. O'Connor EL, White KM. Intentions and willingness to use complementary and alternative medicines: what potential patients believe about CAMs. Complementary Therapies in Clinical Practice. 2009;15:136-140.
22. Verhoef M, Mulkins A, Boon H. Integrative health care: how can we determine whether patients benefit? Journal of Alternative and Complementary Medicine. 2005;11(Suppl 1):S57-S65.
23. Patterson RE, Neuhouser ML, Hedderson MM, Schwartz SM, Standish LJ, Bowen DJ, et al. Types of alternative medicine used by patients with breast, colon, or prostate cancer: predictors, motives and costs. Journal of Alternative and Complementary Medicine. 2002;8:477-85.
24. Smithson J, Paterson C, Britten N, Evans M, Lewith G. Cancer patients'experiences of using complementary therapies: polarization and integration. J Health Serv Res Policy. 2010;15(Suppl 2):54-61.