

FAMILY AND COMPLEMENTARY AND ALTERNATIVE MEDICINE

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Abstract

Families of patients with cancer shape and share in the many and difficult decisions faced following diagnosis, with significant involvement in decisions regarding complementary and alternative medicine. Such decisions may be particularly difficult due to conflicting opinions regarding complementary and alternative medicine and relative lack of medical guidance. Family may act as information seekers, advocates and/or role models, either prompting, enabling or discouraging use by the patient. Complementary and alternative medicine use within a family may promote familial cohesion and functioning, or increase familial distress and conflict. Where outcomes are poor, the ability of the family to care for themselves and the patient may be compromised, adding to the burden of cancer within the community. Some complementary and alternative medicine may offer benefits to family members themselves, either with or without patient use. Evidence is lacking, however, regarding the effect of differences in the experiences or perceptions of complementary and alternative medicine use by individuals in different familial relationships to the patient, or in differences associated with gender, socio-economic or geographical status, ethnic or cultural background, or non-traditional family structure. Moreover, little is known about how families negotiate decisions about complementary and alternative medicine, nor of the long-term consequences of these decisions upon family well-being and functioning. Such knowledge would enable clinicians to better advise patients and their families on treatment choices following a cancer diagnosis.

Complementary and alternative medicine (CAM) use is common in cancer patients with evidence that, at least in breast cancer patients, CAM use has increased significantly over time.^{1,2} In Australia, prevalence of CAM use in cancer patients has been reported to range from 22% to 82%.^{3,4} There is considerable research focusing on the reasons for, and socio-demographic or disease correlates of CAM use.^{5,6} Yet despite reported high prevalence rates, discussions infrequently occur in the oncology setting, such that patients are often left to seek information about CAM, and to take responsibility for making safe and informed decisions.⁷⁻¹⁰

It has been suggested that decisions about CAM are likely to be particularly difficult for patients, in part because of conflicting information as well as varying levels of support for, and divergent perceptions of CAM within scientific and lay discourse.⁹⁻¹¹ In making decisions, patients often rely upon information provided by family members.¹¹⁻¹³ This is unsurprising given familial involvement in cancer care in general - family not only support, but shape and share in patients' decisions, with their involvement in the decision-making process desired and taken for granted.^{14,15} Following a cancer diagnosis, both the patient and family seek out information about treatment options, drawing on various sources such as medical staff, family, friends and the internet.¹⁶ Sometimes family members may be, if not more actively involved in searching for information than the patient. Boudioni reported the majority of inquiries about CAM at a British cancer information service came from

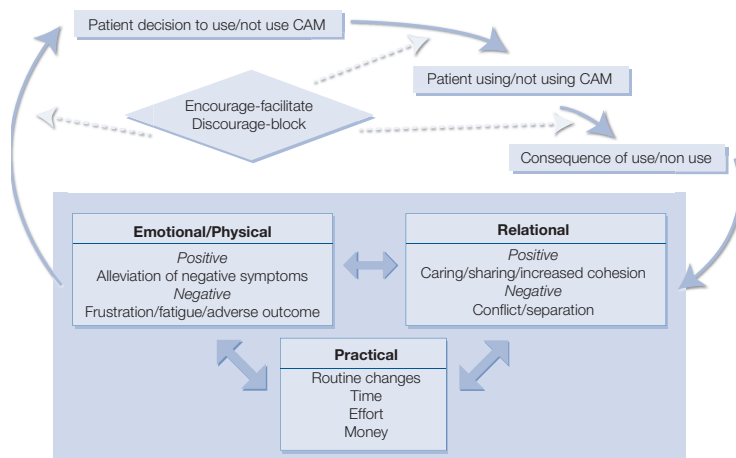
relatives and friends of patients (48%) rather than diagnosed patients (35%).¹⁷ Evidence further suggests family members can play a crucial role when cancer patients decide to use CAM instead of conventional medical treatment, decisions that may reduce the likelihood of cure.¹⁸⁻²¹

Within the medical literature on CAM, family are most commonly discussed as important sources of information, but often within the category 'family and friends' making accurate appraisal of their status difficult.^{3,22-26} Nonetheless, Bennett's recent survey in New Zealand about information seeking and CAM use in cancer patients indicated that surveyed patients mentioned "family and friends" most frequently as a primary information source.²⁷ Similarly, a large European survey about CAM use in cancer patients reported that "friends" (56%) and "family" (29%) were most often named as information sources.²⁸ Although friends appear to contribute information at a higher rate than family, family are likely to be more affected by decisions made, and to have increased opportunities to support or subvert decisions (Figure 1). Despite this, there are few studies explicitly examining familial involvement in making decisions about CAM, and none specifically exploring the consequences of those decisions upon the family.

Family involvement in CAM decisions

Only one study conducted in Sweden has specifically examined the involvement of family in CAM decisions by cancer patients.⁹ Based on interviews with 61 patients and 31 'significant others' (25 family, six friends), four types of

Figure 1: Familial involvement in patient decision-making about CAM.



'other' involvement were identified, all of which saw the family as acting to gather and review information. This process was often prompted by family members' concern about the lack of evidence regarding CAM and consequent difficulties for the patient in making safe, informed choices. Some family chose to inform, but not overtly influence the patient's decision, viewing this as a way of offering support and upholding patient autonomy. Others were more proactive in their assistance, particularly where they held concerns that fatigue or distress might lead patients to make a 'wrong' decision. Interventions varied from gentle suggestions to direct action to affect patient behaviour, sometimes taken without patient knowledge or consent (eg. providing dietary supplements without patient knowledge). Some family members reported working collaboratively with the patient, sometimes mutually participating in chosen CAM practices, with positive consequences including increased familial cohesion and reduced anxiety regarding CAM. Overall, patients in this study reported appreciating others' assistance in CAM decision-making, although it sometimes led to tension. Some patients reported being bombarded with advice, causing feelings of resentment, anxiety, confusion and guilt. Furthermore, while most patients invited family to participate in their decisions, some limited their discussions, either for fear of burdening them, or because patients characterised others as unwilling or unable to provide support. Finally, some patients acquiesced with family opinion or efforts, primarily in recognition of the caring it symbolised, some voicing concern that rejection would be perceived as rejection of the informer.

Many of these themes emerge within other qualitative studies examining CAM use, though not explicitly focusing on familial involvement. An interview study about Chinese-Australians noted that most participants consulted a traditional Chinese herbalist because they were prompted to by family members or friends, and another Canadian focus group study of women with breast cancer, reported cases where family offered either financial or emotional support for participants' CAM use.^{13, 29} A further Australian interview study about treatment decision-making in

palliative cancer patients reported instances where patients stated or implied that familial opinion influenced their decisions regarding CAM.¹¹ Finally, a single case-study report from Sweden noted extensive familial involvement in a liver cancer patient's use of herbal tea, with her husband administering the tea after identifying, locating and purchasing it via the internet.³⁰

Patients' evaluation and uptake of information provided by family, however, may vary dependant on disease or cultural characteristics. In a small qualitative study about CAM decision making in cancer patients, Verhoef et al reported that while new CAM users valued anecdotal information from family and friends, experienced users tempered such advice with their own knowledge, suggesting information from family may become less valued over time,

or with increased experience of disease and treatment.³¹ Similarly, patient responses to CAM introduced by family may be influenced by cultural beliefs about associations between particular CAM and gender roles.³² Broom and Tovey documented how one male cancer patient described his wife's introduction of aromatherapy to him, but rejected it, observing: "Well, why would men want to do that?".³²

Sometimes family involvement in CAM use is problematic. In a qualitative study involving 26 families (including 37 patients with advanced lung cancer and 40 caregivers) Zhang and Siminoff reported three cases in which patients reported familial coercion to take dietary supplements, with a further instance of a daughter physically and verbally insistent that her mother take vitamins.³³ Since it is known family members are often involved in patients' nutritional choices, some have asserted the importance of including and training family members as peer health educators, in order to minimise the possibility of adversely comprising patient wellbeing.³⁴⁻³⁶

There is implicit evidence of familial involvement in cancer patients' CAM decisions in studies assessing 'marital status' in CAM use, though there are differences across studies. For example, Fouladbakhsh et al reported that American cancer patients who were separated or divorced, were more likely to use CAM than married cancer patients, whereas Correa-Velez et al found no difference in marital status, suggesting that CAM use was associated with the number of people living in the house of the cancer patient.^{37, 38} In an earlier Australian study, Begbie et al found that CAM use was positively associated with being married, also suggesting this might be linked to the number of household members, which in turn could stimulate and encourage people to try new things including CAM.³

Further evidence of familial involvement in CAM decisions can be surmised in reports of paediatric cancer patients where parents administer CAM, with mothers typically primary in such decision making.^{39, 40} A recent systematic review indicated that CAM use, particularly use of herbs and dietary/nutritional supplementation, is common in children with cancer, with prevalence rates up to 91%.⁴¹

Despite this, parents' decisions to use CAM for their diagnosed child often happens without the involvement of the paediatrician, and data regarding the decision making processes and outcomes for families is sparse.⁴² Lorenc et al recently observed that the field of CAM decision making for children (with or without cancer) is under-theorised, recommending the use of qualitative methods to redress this.⁴³ Adolescent use of CAM during cancer treatment is similarly unexplored. A single study examining the use of CAM by adolescents without a cancer diagnosis reported that parental use of CAM significantly predicted its use in adolescents.⁴⁴ It was suggested that some adolescents were explicitly introduced to CAM use by their parents, while others imitated the self-care behaviour of their parents without direct recommendation. Data on such choices within the context of a cancer diagnosis is absent.

Consequences of CAM use in the family

Little is known about the prevalence of CAM use by family caregivers of cancer patients, of any impact on patient use, or on patient and/or familial wellbeing.⁴⁵ A study about CAM decisions by male cancer patients reported that female family members acted as role models and sources of information, prompting patients' use of CAM.⁴⁶ Alternatively, some cancer patients who refuse conventional cancer treatment and use CAM instead, may do so because of experiences with close family members affected with cancer who died following biomedical treatment only.¹⁸ Only one American study by Kozachik et al has explored the patterns of CAM use by cancer patients and their family caregivers, following an eight week nurse delivered CAM intervention (guided imagery, reflexology, and reminiscence therapy).⁴⁵ This study found that participants who chose to use a single CAM therapy, used it more consistently over time, suggesting that it was easier to integrate a single CAM therapy into day-to-day life rather than several therapies.

Some studies support observations by Öhlén et al that family provision of CAM might have beneficial consequences for the family, increasing familial cohesion through demonstration of caring for and about the patient, and increased opportunity for active involvement in patient care and treatment.^{9,47,48} Perceived positive effects of CAM use for the family have been reported by Broom and Tovey, who quote a female cancer patient as saying: "I think that CAM, they're such a benefit. Not just for the patient but for the whole family."³² Potential benefit of CAM was similarly reported by a female cancer patient using and encouraging her spouse suffering with multiple sclerosis to use CAM, as she was convinced that it might also help him.⁴⁷ It seems likely, moreover, that reported high levels of distress in caregivers may be helped through use of CAM found to improve psychological status, wellbeing, or overall quality of life in cancer patients, such as aromatherapy, exercise, guided imagery, massage, music therapy, qigong or tai chi.⁴⁹⁻⁵¹

Some negative consequences for family of patient use of CAM have also been identified, and these may compromise the ability of the family to care for themselves and the patient, adding to the burden of cancer within

the community. Broom and Tovey applied an innovative solicited diary/unstructured interview approach to explore CAM users' experiences over time, observing that, for some cancer patients, the use of CAM incurred costs of time, money and effort that sometimes proved onerous for the whole family.⁵² This was particularly evident when CAM included adherence to a strict dietary regime. An American population-based study examining psychosocial correlates of CAM use in adults, also reported that perceived spouse/partner strain and family strain were associated respectively with increased use of biologically-based therapies (including special dietary regimes) and manipulative body-based CAM.⁵³ However, whether partner or family stress prompt CAM use or are a consequence of CAM use is unknown.

Issues for future research

Clearly there are significant gaps in our knowledge of CAM use within families facing a diagnosis of cancer. In addition to those alluded to above, there has been no examination of whether there are differences in the perceptions or experiences of CAM use in spouses, siblings or children of cancer patients, or the effect of any differences on CAM use by patients, despite evidence in other contexts that adult children can experience more conflict with regard to treatment decision-making than spouses of cancer patients.⁵⁴

Research examining these questions with regard to specific cancer diagnoses and stages, as well as gender, socio-economic status and geographical location is similarly absent, as are studies examining CAM use within non-traditional families (eg. same-sex or step/combined families, single parent or separated families, or those without partners).³² Similarly, consideration of ethnic differences in familial involvement in CAM use (either with regard to patient or familial use or both) is vital since the familial input into decision-making as well as perceptions about and use of CAM, varies between ethnic and cultural groups.⁵⁵⁻⁵⁷

Finally, longitudinal studies investigating the nature, extent, and effect of positive and negative consequences of CAM use within the patient's family, or examining how CAM use is negotiated within the family, are required. Knowing if, or under what circumstances, use of particular CAM (by the patient or other family members) will likely add to familial distress and conflict, or alternatively, promote familial cohesion and functioning – with inevitable impact on patient wellbeing – will enable clinicians to better advise patients and their families on treatment choices following a cancer diagnosis.

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