

PSYCHOLOGY OF COMPLEMENTARY CARE IN CANCER: MOTIVATORS, BARRIERS AND OUTCOMES

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Abstract

While the evidence behind effectiveness of complementary therapies is increasing, patients' interest in complementary care is frequently driven by factors other than evidence of efficacy alone and reflects a desire for a different model of care and a different relationship with a health care provider. Patients who seek complementary care tend to be different demographically to those who do not and are more likely female, younger, more highly educated and earning a higher income. Seekers of complementary therapies are more likely to suffer from depression and have poorer physical quality of life. There are multiple barriers to access to complementary care, both provider and patient related. These relate to the insufficient awareness by providers regarding the evidence behind specific therapies or their interactions with conventional care, as well as the expectations placed upon conventional care providers regarding what their role might be. Little is known about how much information patients expect conventional health professionals to provide and there is little agreement on how much would be considered reasonable by the providers themselves. Greater collaboration and communication between complementary and conventional care providers would assist, not only in overcoming the barriers of access, but also building the body of evidence on the potential efficacy of complementary interventions in cancer.

Cancer patients are reported as being among the most common users of complementary therapies.¹⁻³ Complementary medicine is defined as treatments used alongside conventional cancer care to enhance quality of life and support the wellbeing of cancer patients, but not considered to be treatments for cancer itself.¹ This contrasts with alternative therapies, defined as those used instead of conventional approaches to the treatment of cancer.¹ Until recently both terms have been used together, and often interchangeably, under the umbrella term of complementary and alternative medicine (CAM).³ Studies have reported the prevalence rate of CAM use by cancer patients to be as high as over 90%.⁴⁻⁶ The rates vary considerably, depending on the therapies included within the definitions and the populations sampled. In Australia, Begbie and colleagues used reception staff in oncologist specialist consulting rooms to offer a survey of alternative medicine use to more than 500 patients.⁷ Results from 319 patients indicated 22% used some form of 'alternative therapy', and 75% of this group used two or more therapies. Relaxation, meditation, diet therapy, vitamins and positive imagery were most widely used. An important finding of this study was that 40% of patients did not discuss their use of other therapies with their physician, raising concerns regarding the risk of interactions of these therapies with conventional anti-cancer treatments that may not be known to the oncologist.

A survey of cancer patients attending a complementary therapy session at the Gawler Foundation in Victoria, Australia, found that few cancer clinicians initiated

conversations about complementary therapies with their patients, although 57% of 95 respondents said they had raised this with their doctor after a primary cancer diagnosis, and 70% raised this following a secondary cancer diagnosis.⁸ Patients reported clinicians' attitudes towards complementary therapies as mostly negative. Complementary therapies were adopted by 68% of patients after their primary cancer, rising to 87% after a secondary cancer diagnosis. Complementary therapies included naturopathy/homeopathy, Chinese traditional medicine (including acupuncture), dietary supplements and massage. Lifestyle factors such as dietary changes, attending self-help groups, meditation, prayer and spiritual guidance were also reported. Benefits were reported with respect to quality of life.⁸ These results are consistent with findings from other countries,^{9,10} although results should be interpreted with caution because of the issues of representativeness of the patient sample and the scope of therapies covered. Nevertheless, this body of research provides evidence of the significant consumer interest in these therapies.

In addition to the high individual interest, recent years have also witnessed an increase in the societal expectations regarding the provision of complementary treatments. This has been reflected by greater insurance reimbursement for a number of therapies, for example acupuncture and massage, and recently, in the conduct of a Senate inquiry into the quality of cancer care with particular emphasis on complementary and alternative cancer care.¹¹ The inquiry led to a number of recommendations, including

establishment of dedicated funding for complementary therapies, increased research into complementary therapies and improved access to and information about complementary therapies.¹¹ These societal expectations are matched by increasing interest among health care providers as reflected by the establishment of the Society of Integrative Oncology, and emergence of the first integrative oncology centres like the one attached to Sir Charles Gairdner Hospital in Perth.¹²

While the evidence supporting many complementary therapies is increasing,¹³ what is not well established is: whether complementary therapy use is beneficial to some or all cancer patients; what motivates patients to seek (or not seek) complementary therapies in their cancer care (and whether those who do and those who do not differ in some characteristics); what are the main barriers to incorporation of complementary therapies into cancer care for patients and care providers and finally; what implications does this have on cancer practice in Australia. This paper will explore these issues with the purpose of developing recommendations regarding how complementary care and research could be better integrated into conventional cancer care. It is important to emphasise that these issues will be discussed from the perspective of complementary rather than alternative care.

Do complementary therapies improve outcomes?

There is a growing body of evidence supporting the use of complementary therapies in the cancer setting, as summarised in the clinical practice guidelines published under the auspices of the Society of Integrative Oncology.¹³ The available evidence is often limited by the methodological issues of studies conducted – many of them are small, non-randomised studies and thus the level of evidence supporting interventions is often low. This seems to be the case even with regards to the most commonly used therapies. Two recent systematic reviews of commonly utilised strategies, massage and reflexology, found that while these strategies showed promise, the lack of rigorous research evidence precluded any conclusions being drawn.^{14,15} There is a great need to conduct well designed studies into complementary care to provide evidence necessary for such interventions to be included with conventional care or rejected, especially if inclusion were to be supported by government funding based on agreed standards of cost benefit.

While clinicians require high levels of evidence to accept an intervention, patients argue that for low risk interventions, lower levels of evidence may be acceptable. That is, it may not be important whether the benefit was due to the intervention itself or placebo effect, as long as the benefit was possible.¹⁶ While such an approach may not be sufficient from the perspective of decisions regarding reimbursement for these therapies, this observation highlights the need for a greater understanding of what motivates patients

to seek or not to seek therapies, as motivation is only weakly related to the strength of evidence of utility of a particular treatment.

Motivators to seek (or not seek) complementary care

Given its rising popularity, complementary therapy use is clearly addressing a currently unmet patient need. A body of qualitative research has identified a number of reasons and motivators for its use that add to a greater understanding of what needs are met by complementary care. These include: to improve perceived control over one's cancer and resulting treatment,^{10,17-19} reducing the severity of physical symptoms and side-effects, particularly pain, fatigue, nausea and insomnia;^{10,19} boosting immune system functioning;^{10,17} dissatisfaction with conventional treatment;¹⁸⁻¹⁹ and the related need to obtain a holistic approach to healthcare.¹⁹

Patients who seek complementary care tend to be different demographically to those who do not by being more likely to be female, younger (under 50 years), more highly educated and earning a higher income.²⁰⁻²³ Medical variables associated with higher complementary therapy use include poorer health, higher pain, longer time since cancer diagnosis and having a prior history of receiving chemotherapy/treatment.^{20,23} In terms of the psychological 'profile' of complementary therapy users, only cross-sectional studies have been conducted to date and have obtained somewhat mixed findings. Two recent studies have found that complementary therapy users are more psychologically vulnerable, being twice as likely to have symptoms of depression and fear of recurrence.^{18,24} This observation is further supported by studies finding that complementary care users tend to be lower in social support, high in intrusive thoughts and higher in anxious preoccupation.^{25,26} Yet in contrast to these findings, one recent study found that complementary care users had higher levels of fighting spirit and internal recovery locus of control, and did not differ in psychopathology from non-users.²⁶ Of note, quality of life has rarely been examined as a predictor of complementary care use, despite this being identified as a primary motivator. Extrapolating from the general population, longitudinal studies have found that those with poorer physical quality of life are more likely to use complementary care,^{27,28} with one cross-sectional cancer study finding that patients who seek complementary care have poorer total quality of life.²⁵ Overall, as the direction of relationships and causation has not been established, it remains unclear whether the elevated levels of depression observed were caused by, or resulted from, complementary therapy use. This area thus warrants further methodologically rigorous, and longitudinal research to more clearly elucidate the psychological characteristics and outcomes of complementary care use.

The patient's interest in seeking complementary care may be further modified by the influence of a cancer clinician. A qualitative study of United Kingdom male cancer patients about their decisions to use (or not use) CAM, information seeking and types of evidence used, concluded that trusted health professionals could play a significant role in helping patients make informed choices.²⁹ As the standards of evidence used by patients and clinicians to evaluate the benefits or otherwise of CAM may differ,¹⁶ it is possible that patients who do not trust in a physician may be more likely to use therapies against the clinician's advice. This is particularly worth noting as clinicians tend to assume that patients who pursue complementary care are mistrustful of conventional care, and patients themselves fear rejection by their clinicians if they were to admit that they were interested in the pursuit of complementary care.²⁹ An atmosphere of openness and acceptance of patients' interest in complementary care may facilitate disclosure and shared decision making regarding complementary care.

Barriers to complementary therapy use

Despite the well established desire by patients to use complementary care,³⁰ patients and providers encounter significant barriers to incorporating complementary therapy into the care of a cancer patient. To a significant extent these relate to: (1) insufficient awareness by providers regarding the evidence behind specific therapies or their interactions with conventional care; and (2) expectations regarding the role of conventional care providers. As complementary care by definition is 'in addition to conventional care', to ensure its optimal and safe use, including minimising any risks from interaction between conventional and complementary care, conventional care providers need to be able to integrate information regarding complementary care into the overall care of the patient. To do so, they need to be clear about their role in that process and limitations of that role. Little is known about how much information patients expect conventional health professionals to provide and little agreement on how much would be considered reasonable by the providers themselves. Access to reliable information remains limited, reducing the ability of the provider to provide adequate advice and refer clients to appropriate services. The Society of Integrative Oncology, established by cancer care professionals with an interest in complementary care, has published guidelines on standards of complementary care which provide useful information for practising clinicians regarding complementary care in cancer.¹³ In Australia, the Clinical Oncology Society of Australia (COSA) has established a Complementary and Integrative Therapies Interest Group, with the aim of developing resources for clinicians regarding standards of care in complementary care and access to relevant resources in this area. Information is available to society members at <http://www.cosa.org.au/MembersArea/InterestGroups/CIT.htm>

While significant barriers relate to the lack of reliable information regarding evidence for complementary therapies, in some cases access to complementary care may relate to fear on the part of professionals of patient empowerment, increased expectations from the medical profession and the shift from provider driven, paternalistic care, to patient driven care.³¹ In order for complementary care to be accepted and incorporated into the conventional care, an acceptance of patients' role in their care is required by the health care profession.

To be sure, some aspects of complementary care are becoming incorporated into conventional care not by explicit acceptance, but rather by a shift from what is considered complementary, outside the mainstream, to conventional and standard therapy. Examples of such therapies that could be considered mainstream, but are clearly complementary, include evidence-based psychological therapies, particularly guided imagery, relaxation and mindfulness meditation.

Barriers to patient access to complementary therapies mirror barriers to other cancer therapies and include time and cost.³² In addition, a particular challenge for patients is finding a reputable provider who can provide advice regarding therapy and can engage with the conventional provider. Despite common preconceptions, patients are quite concerned about the risk of undermining the therapeutic relationship with their oncologist by pursuing complementary care, and this fear may lead to them abandoning the pursuit of complementary care.²⁹ It is likely that improvement in communication between complementary and conventional providers and incorporation of complementary care services into conventional cancer care may assist in overcoming these barriers.

Implications for clinical practice

Increased societal expectation, patient preferences and the need for greater understanding of the interaction between conventional and complementary care, in the setting of established barriers to access, has important implications for conventional care providers. In order for effective incorporation of complementary care, clinicians need to find a way of facilitating access in the evidence-based setting. Clearly, this task is too great to be undertaken solely by conventional health care providers. What is needed is clarity regarding expectations placed on conventional providers and easy access to reputable complementary providers. Professional organisations, like COSA, can play an important role in clarifying standards and collaborating with professional organisations of complementary care providers to ensure adherence to agreed standards of practice and communication between providers. Both conventional and complementary professionals could benefit from greater understanding of their respective contributions to patient care. Cancer professionals would benefit from easy access to evidence for complementary therapies and training in the field of communication with patients regarding complementary care.³³

No studies to date have explored patient preferences regarding whether the conventional health care system should deliver these therapies and if so, what would be the appropriate model for integration into conventional cancer care. It is also not known what proportion of cancer patients would be interested in complementary care being integrated into their conventional care pathway. Further research in this area is needed.

Finally, many challenges in incorporation of complementary care relate to concerns about therapies used in place of conventional therapies, with the explicit objective of an anti-tumour effect. These therapies, commonly described as alternative medicines, are potentially problematic, as their use is intrinsically linked to rejection of conventional, evidence-based therapies and thus may potentially be harmful and should not be recommended. A clear separation of complementary and alternative approaches may assist clinicians in dealing with these issues.

Conclusion

Complementary therapy use among cancer patients is common and its nature evolving, along with societal expectations of cancer care as a whole. The motivators to use complementary therapy extend beyond evidence for efficacy alone and reflect a desire for a different model of care and a different relationship with a health care provider. There are multiple barriers to access, both provider and patient related. Greater collaboration and communication between complementary and conventional care providers would assist, not only in overcoming the barriers, but also building the body of evidence on potential efficacy of complementary interventions in cancer.

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