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A survey of practices and policies relating to the use of complementary and alternative medicines and therapies in New South Wales cancer services

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Introduction

Up to 83% of Australians who are diagnosed with cancer use some form of complementary or alternative medicine or therapy (CAM)[1], and the number of patients using CAMs alongside or (less commonly) instead of conventional treatment is increasing. [2-4] CAMs include physical, psychological, herbal, nutritional and spiritual therapies. Some are derived from traditional healing systems, and each has different risks and benefits. Cancer patients use CAMs for a variety of reasons: to help relieve symptoms of cancer and side-effects of conventional therapies; to enhance the efficacy of conventional treatments, to achieve a cure; to prolong life; to improve quality of life, or for personal or cultural reasons. [5-7] Patients often decide to use CAMs without discussing this with health care professionals

who are providing standard care for many reasons, including because their health professionals often don't ask.[5, 8, 9,10]

While some CAMs have been shown to benefit patients with cancer, [6, 11-20] using CAMs whilst undergoing conventional treatments can pose significant risks, especially where the therapies are either oral or parenteral.[10, 13, 15, 16, 20, 21] It is important therefore, that practitioners who administer conventional cancer treatments know about the risks and benefits of CAMs that are commonly used in their field of practice, and ask patients about their use of CAMs and ascertain how much they know about the risks and benefits of particular CAMs. Furthermore, CAM use should be monitored and recorded, and health services should have policies in place to address the use of CAMs by patients who are hospitalised or receiving outpatient care. Refusing to acknowledge that patients use CAMs when they are receiving conventional medical care is unrealistic, and it can lead to significant harms arising from the CAMs themselves, from interactions between the CAMs and conventional therapies, or from failure to recognise where CAMs may be beneficial.

With these concerns in mind, this survey was undertaken to examine the practices and policies surrounding the provision, prescription, and regulation of CAM within NSW cancer services.

Materials and methods

Participants

All adult cancer services in urban, regional and remote areas of NSW (both public and private) were eligible for the survey. A list of 65 services was compiled using information from the Cancer Council Australia, the Cancer Institute of NSW, Cancer Council NSW and the Australian National Breast and Ovarian Cancer Centre (NBOCC). Palliative care services and paediatric haemato-oncology services were excluded. Respondents were either directors of cancer services, or other health professionals or administrators who were in a position to answer questions about CAM use and/or policies within each particular service.

Survey

The survey was a structured, self-administered questionnaire developed by the research team from a review of published studies of CAM, including empirical studies of CAM use in hospitals. Following development, the survey instrument was pilot-tested for face and content validity. The first section asked for basic information about the cancer service (e.g. whether it was located in public or private hospital, and whether it was in an urban, regional or remote location). The remainder was divided into five sections, each beginning with a "Key Question":

1. *When patients are admitted or have their first consultation with your cancer service/hospital, is it expected that they will be asked about*

complementary/alternative medicines they may be taking or complementary/ alternative therapies they may be receiving?

2. *Does your cancer service/hospital provide or prescribe any complementary/alternative medicines or therapies to haemato-oncology patients (in-patients or out-patients)?*
3. *Does your cancer service/hospital permit any CAM practitioners from the community (i.e. not employed by your hospital) to treat in-patients?*
4. *Does your cancer service/hospital permit any in-patients to bring their own complementary medicines into the hospital? (e.g. herbal medicines, complementary dietary supplements).*
5. *Does your cancer service/hospital have any formal policies about CAM?"*

Each key question was followed by a series of multiple-choice questions that probed for further information. Some questions also allowed free-text responses.

Data collection

The questionnaire was posted with a covering letter, two information sheets, and a pre-paid, return-addressed envelope. After four weeks, non-responding services were sent a follow-up email with an electronic version of the survey attached, and a request to complete and return it by email, fax or post. After a further four weeks telephone calls were made to the contact at each institution that had not responded. A final round of telephone calls was made at the end of March 2009.

Analysis

All returned surveys were de-identified and the data was entered in to SPSS[22] for analysis. Descriptive statistics (i.e. counts and percentages) were obtained for all variables.

Ethical approval

The survey was approved by the University of Sydney Human Research Ethics Committee.

Results

Of the 65 eligible cancer services, 43 (66%) responded to the survey, 32 (74%) public and 11 (26%) private. Almost half (n=21, 49%) were located in urban areas; 20 (46%) were located in regional areas and 2 (5%) were in remote areas. The distribution of non-responders was similar to that of responders by sector and location (Table 1).

Table 1. Comparison of responders and non-responders by sector and location

	Urban	Regional	Remote	Public	Private	Total
Responders	21 (49%)	20 (47%)	2 (5%)	32 (74%)	11 (26%)	43 (100%)
Non-responders	12 (55%)	10 (45%)	0 (0%)	16 (73%)	6 (27%)	22 (100%)

Of the cancer services that responded to the survey, six (14%) indicated that they had formal policies about CAMs; 27 (63%) indicated that they had no formal policies, and in nine (21%) services, the respondent indicated that he or she did not know whether or not the service had any such policies.

Cancer services enquiring about CAM use on initial contact

In the majority of services (n=33, 77%), it was expected that patients were asked about their use of CAMs, either on admission to hospital and/or at first outpatient consultation. This proportion was higher in private services (10/11, 91%) compared to public services (23/32, 72%). It was also higher in services located in urban hospitals (18/21, 86%) compared to those located in regional (14/20, 70%) and rural hospitals (1/2, 50%).

Cancer services that provided or prescribed CAMs

Of the 43 cancer services that responded to the survey, eight (19%) reportedly provided and/or prescribed CAMs for their patients. Of these, five were public, three were private, two were urban, five were regional and one was remote. Four of these eight services provided rooms or facilities for CAM practitioners to treat patients, and one cancer service had a dedicated CAM centre. This centre was located in a public, urban hospital, and provided services to in-patients, out-patients, lay carers and staff.

The provision of CAMs was funded in a variety of ways. Two services charged patients for the services and/or products; two services were supported by hospital funding; two services were supported by donations from charitable organisations, and one service was supported by funding from the State Government.

Most services reported that more than one group was involved in the administration and organisation of CAM services. Five centres nominated hospital nursing staff; three centres nominated allied health professionals, and two centres nominated both CAM professionals and volunteers.

Three of the eight cancer services required CAM practitioners to be formally accredited by their relevant professional bodies. Formal credentials were not required in the services that employed either nursing or allied health professional staff as CAM practitioners. Individual liability insurance for CAM practitioners was required by two cancer services, but in other

cases the practitioners were covered by hospital insurance either as volunteers or as employees.

Cancer services providing CAMs used a combination of methods to ensure patients were aware of this option, including information leaflets, hospital websites, posters, and informal advice from health professionals working within the cancer service. One cancer service produced a DVD with information about CAM services, and one conveyed this information via hospital newsletter. The main reasons that informants gave for providing and/or prescribing CAMs were: patient well-being (seven services); patient demand (four services), respect for cultural beliefs (three services) and evidence of efficacy of selected CAMs (three services).

Specific CAMs provided by the cancer services

Four cancer services provided Massage Therapy, three services provided Aromatherapy, three provided Meditation and three provided Reiki. Qi Gong, Healing/Therapeutic Touch, Reflexology, Tai Chi, Art Therapy, Music Therapy and Indian Head Massage were provided by one service each. One service provided unspecified complementary medicines, and one provided "Supportive therapies whilst on chemotherapy, e.g. Lactobacillus rhamnosus GG while on 5 Fluorouracil". When asked why they provided or prescribed these particular CAMs, six services cited patient well-being, five cited evidence of safety, four cited efficacy of the CAM and patient demand, and two cited respect for cultural beliefs and practices.

Recording CAM treatments in medical records

In seven of the eight cancer services, details of CAMs that had been provided or prescribed by the cancer service were recorded by nursing staff in patient's medical records. Five services recorded details for in-patients; five recorded details for out-patients, and three services recorded details for both in-patients and out-patients. One service also permitted CAM practitioners who were not employed by the hospital to make entries in their in-patients' hospital records.

Treatment of in-patients by CAM practitioners from the community

Only four cancer services permitted CAM practitioners from the community to treat in-patients. One was located in a public hospital and three were located in private hospitals. All four services required medical or nursing staff to record details of CAM treatments in the patient's hospital records, and one also permitted the CAM practitioner to do so. Three of these four cancer services placed restrictions on the CAM practitioners, requiring them to be hospital-approved, accredited, and have liability insurance. Two services further required the direct permission of medical staff for the CAM treatment.

Cancer services permitting in-patients to bring in their own CAMs

Of the cancer services that responded to the survey, about half (n=24, 56%) permitted in-patients to bring their own CAMs into hospital. One in five services (19% – two urban and six regional) did not know whether patients did this, and one in four services (26% – seven urban public, two urban private and two regional public) did not permit it.

Medical approval of CAM use by in-patients

Of the 24 services that allowed patients to bring their own CAMs into hospital, more than half (n=15, 63%) expected the treating doctor, or other medical professional staff, to routinely counsel the patient or guardian about their use of CAMs. A majority of these services (n=17, 71%) also required that the treating doctor grant formal approval for each patient's use of CAM whilst in hospital. Seven services permitted patients to continue using a CAM that their clinician had not approved. Only two of these services required that a notation be made in the patient's records that the CAM was not approved for use. Three services required the completion of a "waiver of hospital responsibility form" or equivalent.

Of the 17 services that required formal approval from the treating doctor for the use of CAMs by in-patients, 10 stated that the supply of unapproved CAMs was left to the patient; five were not sure who supplied unapproved CAMs, and 2 respondents did not answer this question. Only one cancer service assumed responsibility for storing the unapproved CAMs; the majority (11/17, 65%) left the responsibility for their storage to the patient. A majority (11/17, 65%) also reported that patients self-administered unapproved CAMs. Four respondents were uncertain as to who administered them.

If the treating doctor sanctioned the use of a particular CAM, most of the 17 services (n=13, 77%) documented its use in the patient's hospital medication chart (six services) or in other specified locations including admission notes, medical records and nursing notes (five services). Approved CAMs were supplied by the patient in 12 of these 17 cancer services. One service was responsible for supply. Three cancer services were responsible for storing approved CAMs, and ten required the patient to store their own. Approved CAMs were self-administered by the patient in most (11/17, 65%) services. Medical staff administered approved CAMs in two services, and nursing staff administered the CAMs in three services.

Discussion

The results of this survey indicate that the majority NSW cancer services are aware that many patients with cancer use CAMs or access CAM services. In the majority (77%) of responding NSW cancer services, it was expected that medical staff routinely ask patients about CAM use, and just over half (56%) of the services specifically permitted in-patients to use their own CAMs in hospital, with most informing patients of their 'right' to do so. However, while many services enquire about patients' use of CAM, few demand formal

medical assessment of CAMs, or education of patients regarding the risks and benefits of using them. And of the cancer services that do allow patients to take their own CAMs while in hospital, few take responsibility for safe storage of the CAMs, and monitoring and recording of use is infrequent.

There is evidence that some CAMs may provide benefits for patients with cancer by providing symptom relief, by reducing psychological distress and/or by improving well-being. (6, 10-19) CAMs may also carry significant risks, however, either when used alone or when combined with conventional medical treatment. These risks include infection, fractures, bleeding, hepatic failure, adverse drug reactions and possibly tumour formation or recurrence. (12, 14, 15, 19-21) Yet the survey results reported above show that only a minority (17/43, 40%) of services required medical approval of in-patients' CAM use whilst in hospital, and of these, less than half (7/17, 41%) documented the use of any unapproved CAM in medical records. The results also indicate that the supply, storage and administering of CAMs (both unapproved and approved) was largely unmonitored, and left mainly to the patient.

This survey has a number of limitations. Firstly, it relies on self-reported data. Secondly, whilst the response rate (66%) is acceptable, it does leave room for selection bias (although it is reassuring that the demographic characteristics of non-responders were similar to responders as shown in Table 1). Thirdly, the absolute size of the sample was small, which obviated the use of statistical tests of significance in our analysis. Finally, we cannot be sure that each respondent was the ideal person to answer the survey questions.

The findings of this survey are nevertheless important because they suggest that not enough attention is being paid to the monitoring and control of CAM use in NSW cancer services. This is concerning given that a significant number of patients with cancer use CAMs alongside their conventional treatment, that certain CAMs are associated with significant (and often uncertain) risks, and that there is a high likelihood of interaction between CAMs and conventional therapeutic agents. In order to ensure that patients receive care that maximises benefit, minimises harm and is consistent with their values and life circumstances, then effective mechanisms to monitor and control CAMs need to be carefully considered, planned and widely implemented within both inpatient and outpatient haemato-oncology services. Given the complexity of this issue, it is likely that a number of policy and practice changes will be required. These should include, for example, policies that make it compulsory for hospital staff to ask patients about their use of CAM, to document CAM use in patients' records, and to ensure safe storage of CAMs that patients bring into hospital.

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