Complementary and Alternative Medicine (CAM) and cancer user groups in the Australian context: A Case Study of an Oncology Support Group in NSW.

Innovative Health Technologies Programme
Travel Fellowship Report

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'*The Mediation of Complementary and Alternative Medicine (CAM) in and by Cancer User Groups and Charities: UK and Pakistan*'

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Acknowledgements

This report is based on exploratory fieldwork carried out with a cancer support group in New South Wales, Australia, during November 2003. It represents an extension to the Economic and Social Research Council (ESRC) project *The Mediation of Complementary and Alternative Medicine (CAM), in and by Cancer User Groups and Charities: UK and Pakistan,* and was funded by a Travel Fellowship from the ESRC Innovative Health Technologies (IHT) Programme. The study was made possible through the generous support and co-operation of patients and staff connected with the fieldwork site. Assistance with the organisation of the trip, ethical approval in Australia, and fieldwork planning were provided by Dr Jon Adams (School of Medical Practice and Population Health Centre for Clinical Epidemiology and Biostatistics, University of Newcastle, NSW), and the project would not have been possible without his help.

Introduction

A strong collaboration is developing, around the shared interest of the sociology of complementary and alternative medicine (CAM) and cancer, between the University of Leeds CAM research group, UK (led by Philip Tovey) and CAM researchers at the University of Newcastle, Australia (led by Jon Adams). This IHT travel fellowship was used to build on and develop this existing collaboration. It provided an opportunity for a research fellow from the Leeds CAM group (John Chatwin) to visit Australia and gather preliminary comparative empirical data that will feed into the existing ESRC / MRC project *The Mediation of CAM in and by cancer user groups and charities: UK and Pakistan.* Specifically, it allowed for a month of qualitative fieldwork to be conducted with a cancer user group in New South Wales.

Background

Despite advances made by conventional medicine, interest in complementary and alternative medicine (CAM) continues to grow at an exponential rate (Mcgregor and Peay*,* 1996). Its popularity amongst users, particularly in prosperous Western countries, has similarly been undiminished despite conflicting signals from within the orthodox medical establishment (Tovey, 1997). Although CAM is increasingly manifest across a whole range of healthcare settings, there is strong evidence to suggest that cancer care represents an area in which it is particularly widespread (Kohn, 1999). Similarly, cancer care has traditionally been an area in which self-help groups play a significant role, and it is through the activities of these groups that many cancer patients, their carers and other stakeholders engage with and access CAM.

The ESRC / IHT programme project *The mediation of CAM in and by cancer user groups, networks and charities*: *UK and Pakistan* is currently mapping the, as yet, largely unexplored socio-dynamics of cancer user-groups and the mechanisms by which they inform stakeholders, and supply CAM services. While it has become evident that group-based mediation in cancer care plays a significant role in the propagation of CAM in both developed and developing countries (Chatwin and Tovey, in press), there is still a lack of data relating to how broader structural variations within the healthcare provision of different countries may influence group-based practices. Wide disparity exists between countries in relation to the organisation of healthcare provision – ranging from systems which are largely state funded, through to ones which are almost wholly privately funded. This creates the need for the analysis of embedded groups to not only account for relative group dynamics, and the ongoing discourse between orthodox and complementary medicine, but also the contextualisation of processes within a local / global socio-medical continuum.

In Australia, as in most other developed countries, cancer user-groups play a key role in the propagation of CAM services and patient access to CAM. The Australian health care system, however, is an idiosyncratic hybrid of private an public provision, and this has meant that important variations relating to the integration of CAM - or more specifically, particular types of CAM – have developed.

This report is based on an exploratory field trip to study the activities of a cancer support group in NSW: *The All Saints Hospital Meditation Group*[1] the members of which are actively utilising CAM (in this case, meditation), as part of their treatment. The purpose of the visit was to gain a broad picture of the role that cancer user-groups may be playing in providing and informing about CAM in the Australian context, and to collect sufficiently rich data to produce a stand alone case study of the host group. This will augment work currently underway on the role of cancer user-groups and CAM in the UK and Pakistan (see above) by providing comparative data from another late-modern society (i.e. one that is developed but has a different health care structure to the UK).

Proposed research activities

Fieldwork was essentially planned to provide a self-contained case study of the meditation group, and the research schedule was as follows:

Pre-fieldwork

- Dr Phil Tovey to make a preliminary trip to Australia to liaise with Dr Jon Adams at the Centre for Clinical Epidemiology and Biostatistics (CCEB), University of Newcastle, NSW, and identify possible fieldwork locations (i.e. cancer user groups or networks using CAM).
- Isolate one group and make initial approaches to the organisers regarding the research.
- Confirm group suitability and access.
- Apply for ethical approval from the relevant regional organisation in Australia (Hunter Area Research Ethics Committee).

Fieldwork (conducted in Australia)

- Conduct preliminary meetings / interviews with group organisers to refine fieldwork method and approach.
- Attend group meetings as a participant observer.
- Recruit a sample of patients, group members and other stakeholders for in-depth one-to-one qualitative interviews.
- Conduct interviews with these individuals.
- Collect relevant document and archive materials relating to group activities and group development etc.

Post-fieldwork (conducted from the UK)

- Transcription of interview recordings.
- Collation of field notes and analysis.

[1] Although the broad geographic details in this report are accurate, the name of the meditation group and the host hospital have been changed.

Other activities while in Australia

- Explore potential for future collaboration with Dr Adams and other researchers at the CCEB.
- Develop ideas for publications arising from themes highlighted during the fieldwork.
- Continue discussions on the development of a funding application to conduct a full comparative study in Australia.

Activities actually undertaken

The activities actually undertaken closely matched those proposed, and all targets relating to the collection of data, networking, and planning for future work were met and exceeded. Specifically, it was possible to complete more observational fieldwork and in-depth interviews with members of the case study group than was originally envisaged.

The fieldwork

In order to be methodologically compatible with the parent study, the fieldwork was designed to mirror the approach currently being utilised in the UK / Pakistan project. A wide range of data was therefore collected in order to capture as complete a picture as possible of the group environment; its activities; its members; its position as part of the hospital; the dynamics of its location within the Australian socio-medical paradigm; and the extent to which it could be regarded as being a representative example of groups of this type.

Specifically, data collection focused on:

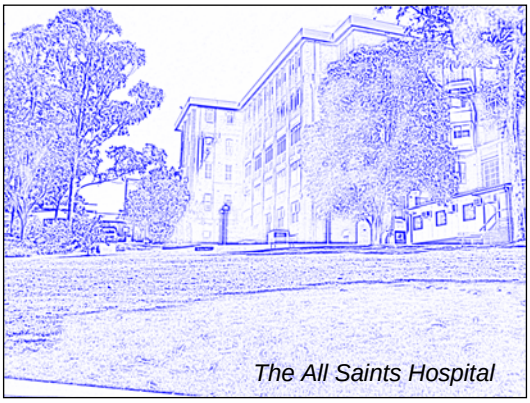
- *Participant observation of group activities* (i.e. taking part in the structured meditation sessions that the group provided and the informal pre / post meditation interactions within which these activities were embedded).

- *Qualitative interviews,* both informal and semi-structured, with group organisers, group members and other stakeholders.

- *Document analysis*, including the collection of publicity material by and about the group, reports, policy / intent statements, group handouts and other documentation such as internal evaluation questionnaires which the group utilised.

The All Saints meditation Group

The meditation and relaxation group based at All Saints Hospital, NSW. All Saints is primarily known locally as a centre for oncology services and offers a range of auxiliary and support services for cancer patients and their carers including occupational therapy and genetic counselling. Within the hospital grounds is the Mercy Hospice which provides pain and symptom management, short time respite care and terminal care. The All Saints group was chosen as a case study site from a shortlist of five possible CAM / cancer user-groups in the NSW area. The main reasons for its inclusion were that it was relatively small; its provision of CAM was straightforward (i.e. it ostensibly focused on providing only one activity – meditation); its client base was largely drawn from the local area, which would simplify the logistics of interviewing group members; it was structurally positioned within a mainstream health setting; and it could realistically be expected to be representative of similar groups in other Australian oncology settings. Importantly too, the group was known to meet on a weekly basis, which allowed for a number of participant observation sessions to be incorporated into the relatively short time available for the fieldwork (1 month).



The All Saints Hospital

Structure and origins

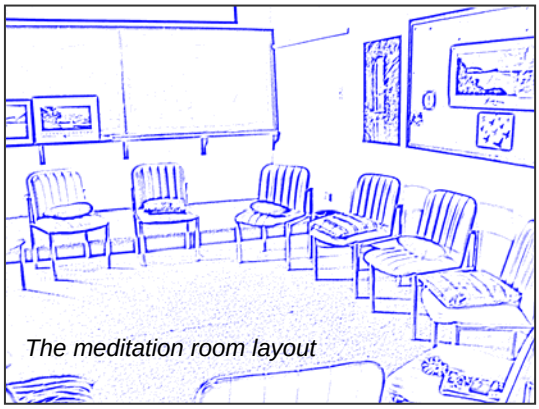
The group was originally started in 1998 by two full-time members of the hospital staff – an occupational therapist and a social worker. However, its activities only represent an informal extension to their regular therapeutic roles. They reported being motivated partly by a perceived need for this type of support service within the hospital, and partly because both had had positive experiences of selectively incorporating meditation into their therapeutic contact with cancer patients and their carers. Their group is affiliated to the hospital to the extent that a room is made available for meetings and publicity material carries the official hospital logo. However, no direct funding provision is provided, and the group is not included in the list of support services routinely advertised in hospital literature or on the hospital website. Participation in the meditation group is free, and open to all oncology and haematology patients attending the All Saints hospital and the Mercy hospice. As with a number of similarly placed groups in the UK, the group has a semi-official position within the official hospital organisational structure but enjoys no formal mechanism for patient referral. The main avenues by which patients find out about the group being through posters placed around the hospital, informal referral by hospital staff, and information leaflets left in wards and waiting rooms.

Group processes

An effective way to illustrate some of the significant points which developed during the fieldwork is to tie these in with a sequential description of an 'average' group meditation meeting. All of the sessions observed during the fieldwork conformed broadly to the following format and interview data confirms that these were representative of routine meetings.

1. Arrival of participants and informal talk period

Meditation group meetings are held every Thursday morning at 11.00 in a small room in the basement of the hospital. Sessions last around an hour. Hand drawn signs mark the way and these double as information posters advertising the group. The door to the meditation room (which is used as a seminar room for the rest of the week) is left open for half an hour or so before activities are scheduled to begin, and members utilise this time for informal socialising – at least one of the facilitators being on hand in order to catch newcomers and informally explain the workings of the group to them. As people arrive they take up a place on one of the ten or so chairs arranged in a circle facing inwards. This arrangement appears to be relatively ubiquitous in groups of this type, although interestingly, long term members reported that when the group first started, chairs had been arranged in rows facing the facilitators, and it was only at the suggestion of members that the current arrangement was adopted.



The meditation room layout

2. First guided meditation

Both facilitators share the job of guiding meditations and work closely together to produce sessions that are not overtly prescriptive, yet follow an underlying structure. At the start of a session, the group is asked if there is any particular style or type of meditation that they would like to work with that day. The facilitators have developed an extensive repertoire of meditations, ranging from relatively simple visualisations and breathing techniques, through to more esoteric routines which focus, for example, on particular colours or sounds as a means of stimulating healing. The type of meditation offered can therefore easily be tailored to the makeup of the group on any given day. The facilitators are very conscious of not displaying, or being seen to encourage, any particular religious content in the material that they utilise – a significant number of the relaxation and breathing techniques that they utilise, for example, are derived from medical, psychological and physiological sources rather than esoteric ones. In common with similarly placed groups in the UK, the meditative process is presented (in both group interactions, and in publicity material) simply as a neutral and effective means of reducing the damaging side-effects of stress, not as a spiritual endeavour. Projection by participants of strong 'new age' or 'alternative' perspectives onto the activities of the group is not actively encouraged – the facilitators feeling that this kind of group image would not only

alienate more conventionally minded participants, but might also undermine the credibility of the group within the hospital. Problems with group dynamics relating to past members who would not accept this convention were reported. Significantly, however, the majority of group members interviewed (including the facilitators) openly expressed personal belief systems which were very much more in line with holistic and 'alternative' paradigms.

3. Break / de-brief

The first meditation or relaxation exercise lasts for around half an hour. At the end of this time, the facilitator 'brings back' the group and asks individuals how they felt about the experience, whether it was beneficial to them etc. Members are not required to make any comment at this point if they do not wish to do so, but due to the interactional dynamics of the process (with all participants asked in turn), people do routinely feel they should make some form of comment. Around ten minutes is given over for the process. This part of the session was one area in which the views of group members differed. Some regarded the break (and the 'coming out' of the meditative state which this involved) as being unnecessarily distracting – making it difficult to regain a significant level of relaxation later in the session. Others liked the chance to talk about their experiences and give feedback about how they found particular meditative techniques. The facilitators were aware of this problem but concluded that on balance, splitting the session into two parts was useful as it allowed for contrasting types of meditative exercise to be provided – patients who had difficulty with one might 'connect' with another. Similarly, the group assessment questionnaires which were regularly given to members in order to canvas their opinions had highlighted that the idiosyncratic delivery techniques and voices of the facilitators were preferred by different patients. By extension, this had an effect on the therapeutic benefit that singly guided sessions might provide to a given individual.

4. Second meditation

Following the feedback session, another guided meditation was read out by the second facilitator. This was routinely planned to contrast with the first one, although again, the group was asked if they had any preferences before it was started. Around twenty to thirty minutes was allowed for this part of the session.

5. Group experiential discussion

Following the conclusion of the second meditation, more time was allotted for people to discuss their experiences. Some participants preferred to leave at this point and there were no overt restrictions on them doing so. The discussions that took place during this period were generally much looser than in the first break and represent a significant crossover in the overt functioning of the group. Talk ostensively focused on the specifics of members current cancer experiences, and the meditative exercises. Patients often, however, shared CAM related information during these periods (such as aspects of therapeutic diets they were engaged in, or other therapies they were using). This highlights the dual role that this group

(and other groups that operate from within conventional medical settings) can play. While their overt function is the provision of an 'incorporated' or conventionally sanctioned form of CAM (i.e. meditation). Embedded within this is often the facilitation of an interactional arena in which 'alternative' and potentially subversive (in terms of dominant medical paradigms) information is freely exchanged.

Significant findings and recommendations for future research

Several themes have arisen from the data that will directly inform current work on the dynamics of cancer user groups and CAM. The study has also raised issues which need to be addressed by further research:

Group position and system restrictions

Against the backdrop of growing trends towards the integration of CAM into the mainstream (particularly in cancer care) the data has highlighted similarities between restrictions on the development of CAM based services within orthodox healthcare structures in the UK, and those found in Australia. Groups like the one at the All Saints operate in a relatively unsupported and marginalised capacity within an orthodox hospital environment; the CAM services that they provide (or provide information about) being carefully adapted so as not to jeopardise either the continued tolerance of the group within the orthodox setting, or the credibility of the facilitators within their professional roles. This theme of self-selective CAM incorporation by different types of group (i.e. ones that operate within conventional health care structures, and ones that are relatively independent of them) has significant implications in terms of the contextual definition of therapies in relation to orthodox medicine.

Direct comparative work

Initial findings in Australia suggest that although the dynamics of the relationship between orthodox healthcare structures and cancer / CAM related support group activities appear to be very similar to those found in the UK, there are significant differences. These relate particularly to issues of gender balance within groups; the ascendancy of certain types of CAM over others in comparable group environments; and the role that access to particular CAM related group services may play in attracting cancer patients towards particular oncology centres. Addressing these structural issues makes the development of an accurate and globally contextualised paradigm of CAM group roles dependent on further country (and health system) specific research.

Initial analysis of data from this study has also suggested that there is definitely potential for comparative work focussing on the therapeutic narratives that cancer patients experience as they engage with CAM. Are there significant differences between the experiential trajectories of people who utilise group services in Australia and those that do so in the UK? And to what

extent do underlying cultural elements (such as the seemingly country specific popularity of particular types of CAM) interact with pragmatic reasoning related to provision and supply?

Refinement of group paradigms

Preliminary analysis of interview and document data also points to an organic and apparently ad hoc development of CAM based cancer support groups positioned outside organised health system networks. This is very similar to the situation reported in the UK, US and many European countries. Similarly, it is evident that in Australia these types of group routinely have comparatively 'esoteric' and overtly 'alternative' agendas. This confirms that inter-(health) system paradigms of group development which are currently being developed need to be informed by models that incorporate the idiosyncratic yet simultaneously homogenous nature of groups that operate beyond the conventions of mainstream medical convention.

Plans for future work and collaboration

- As a result of the fellowship, several collaborative publications with Dr Adams and Dr Tovey are currently in progress. These will be based on a more detailed analysis of the data collected during the trip.

- The Australian exploratory data will form the basis for a comparative section to be included in a proposed book (*Complementary medicine in cancer care: an international analysis of grassroots integration)* focusing on the findings of the ESRC / IHT project *The mediation of CAM in cancer user groups and charities: UK and Pakistan.*

- A collaborative proposal for a full length comparative project based on the data provided by the fellowship is being developed between the Leeds and Newcastle CAM research groups.

- Plans are underway to collaborate with Sara Burns from the Newcastle CAM group to submit a grant proposal for work focusing the interactional arena of CAM therapeutic interventions (specifically *music therapy)* in the support group environment.

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