INNOVATIVE HEALTH TECHNOLOGIES PROGRAMME

The Mediation of Complementary and Alternative Medicine (CAM) in and by Cancer Support Groups, Networks and Charities: UK and Pakistan

KEY FINDINGS

What is the nature of involvement with CAM in cancer patient groups, health charities and networks? What are the processes underlying decision making on CAM, and the selection, interpretation and utilisation of information about it? To what extent, and in what way do patient groups and networks act as advocates, gatekeepers, and providers of CAM? Are groups challenging inequalities in cancer care and access to CAM? Do patient groups and networks constitute innovation? How do these processes vary between the UK and Pakistan?

RESEARCH FINDINGS

- In terms of organisational structure, two main types of group are concerned with mediating CAM: ones that are incorporated into mainstream healthcare systems, and ones that are largely independent of it.
- Although cancer is reportedly at the cutting edge of integration, the number of CAMs available in support group settings (in terms of different types) is relatively small and routinely consist of three or four 'safe' therapeutic approaches.
- 'Gate keeping' activities in the group context often emerge as a result of the desire to ensure that patients are not exposed to treatments and procedures that might be damaging. They are not always overt or planned. In some groups it is connected with maintaining a level of credibility and acceptance (in terms of wider orthadox healthcare networks).
- There is some evidence that for conventional health professionals, involvement in CAM based support groups can be a 'legitimate' means by which they participate in CAM related activities without damaging their professional position.
- Although CAM and traditional medicine play an important role in both the UK and Pakistan, direct comparisons between the two countries are difficult in the context of 'groups' because in Pakistan, nothing approximating the support networks found in the west exist.

RESEARCH TEAM

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The nature of involvement

Group types

There are a wide variety of self-help groups, networks and charities concerned with providing CAM services for cancer patients. These range from organisations which are essentially divisions of conventional healthcare (such as groups based in oncology units or hospitals), through to 'grass roots' groups that have no affiliation to local health networks. A significant finding has been that there are basically two distinct categories into which any given group will fit:

Type 1 groups are groups that were established organisations before branching out into providing CAM services. These are often formulated along 'traditional' socio-medical lines, have strong NHS connections, and the incorporation of selected CAM therapies does not have any significant impact on their organisational direction or ethos.

Type 2 groups have an overtly holistic agenda. They are generally much smaller in terms of membership, less integrated into wider health networks, and under-funded when compared to their NHS affiliated partners. Their independence allows them to more readily reflect an underlying CAM / holistic ethos because CAM forms an integral part of what they do, and they are generally run and organised by CAM therapists.

Decision Making

There are a number of issues here. Although reportedly at the cutting edge of integration, the types of CAM that are routinely offered in the support-group context are relatively small and well defined. They by no means provide an accurate reflection of the relative popularity of different therapies in wider society. This is especially true of type 1 groups. In these settings the process of decision making on CAM may simply represent a choice between one or two 'approved' therapies within an overarching model of conventional treatment. 'Choice' is provided and controlled by individuals in a position of medical authority, and so is essentially, between selected and approved CAM therapies, rather than the more significant choice between CAM and conventional medicine per se.

Gate-keeping

As a first point of contact for many cancer patients engaging with CAM, support-groups and organisations will, by default, provide a degree of 'gate-keeping'. This activity, while more overt in type 1 groups, is also intrinsic to type 2 groups. There are, however, significant differences in how this is manifest across types. In type 1 groups most gate-keeping is a pragmatic strategy to ensure that patients are not 'exposed' to practices that might be medically damaging. This is certainly the way in which many health professionals (group facilitators / Macmillan nurses etc.) view the process. When dealing with the introduction or provision of CAMs into a group they tend to operate in a *protecting* rather than *providing* mode. This carries over into the tenor with which information on CAMs is delivered. There is a definite sense within some areas of cancer care that CAM in general is viewed as a kind of homogenous danger that 'vulnerable' patients need to be kept away from.

Conceptualisation

Therapists / organisers

The nature of cancer - i.e. often a life threatening disease - produces or attracts a particular kind of CAM therapist. This is reflected in the underlying world-views and life narratives that therapists report. In our data, a significant number of them (and other stakeholders) recount how their connection to a group or to CAM activities in general was the result of serendipitous or 'guided' coincidence. Involvement for therapists and organisers is rarely (overtly) motivated by money or career progression, and much CAM work in the field is offered to group members (i.e. patients) for free or at greatly reduced rates. This is particularly prevalent in the very small groups which may revolve around one or two key stakeholders.

Patients

Patient rationales for involvement are similarly straightforward. The primary reason why many patients *initially* engage with the CAM therapies that support groups offer is simply the desire to

deal with their cancer, or to alleviate the side effects of conventional cancer treatments. Strongly held beliefs in the efficacy of CAM over conventional treatments are evident, but for most patients the CAM they access through support groups is just another avenue to be pursued in the hope that life can be prolonged, or quality of life maintained.

Innovation

There is some evidence that groups are providing innovative means of contact between orthodox practitioners and CAM therapists. In terms of integration, for example, support groups can be seen as a legitimate route by which orthodox practitioners may become involved in CAM without damaging their professional position. Other examples of innovation or innovative developments are the promotion of egalitarian / member led group facilitation (i.e. attempting to be hierarchy free), and practical activities such as the use of recordings of guided therapy sessions (meditations, for example) for patients who are too ill to attend group sessions.

Pakistan

As anticipated, the study has confirmed that CAM/Traditional medicine (TM) plays a major role in cancer care in Pakistan. Understandably, however, the situation there is significantly different to that encountered in the UK a notable contrast being the complete absence of the 'support groups' that are ubiquitous in western cancer care.

Pakistan has a unique medical system whereby patients may be treated within a number of diverse therapeutic disciplines. While allopathic medicine is frequently used for serious conditions, people often use CAM or traditional medicine (TM) in combination with, or instead of, allopathic medicine. Pakistan has a long history of TM use in conjunction with western oriented practices. And alongside practices that have parallels with those used by cancer patients in the UK (i.e. homoeopathy, healing, etc.), there are several major CAM / TM modalities that are less well known. In particular: *Hikmat.* (also known as 'Greek medicine' or Islamic tibb); *Spiritual healing*, and *Dam Darood* (practices that depend on prayers and the use of tokens and charms); *Prophetic medicine.* (based on the recorded sayings and actions of the Prophet Muhammad).

The nature of cancer and the role of CAM / TM therapies

In Pakistan CAM / TMs were perceived as being 'preventative' and 'long-term' options, whereas in the case of cancer, a 'harsher' and 'immediate' approach was considered more appropriate. There were, however, mixed views about the degree to which CAM / TM therapists were capable of dealing with such a serious condition. In most cases, allopathic medicine was regarded as the only real curative option. Although some patients consulted traditional healers initially, allopathic medicine was usually perceived to be vastly superior in its ability to treat cancer.

Socioeconomic status and treatment choices

Cost of treatment and issues of access to allopathic medicine emerged as important issues. The majority of the patients indicated that cost (or low cost) was a factor in both their use of, and their community's use of, CAM / TM. Although most viewed allopathic cancer treatments as superior, they also recognised the inaccessibility of such treatments for many segments of Pakistani society. Thus, effectiveness of treatment, although important, would need to be sidelined for many patients due to issues of cost.

Communication and CAM / TM versus modern medicine

Research in CAM in western nations has illustrated that use of CAM is often associated with the tendency for CAM therapists to have more effective communication skills, resulting in more effective client/practitioner relationships. However, our Pakistani data revealed considerable heterogeneity in experiences of the client/patient relationship. In fact, considerable satisfaction was expressed in relation to the ability of doctors to communicate. In some cases, lower caste or poor patients did report being able to relate better to healers (i.e. Hakeems), due to their comparable social status.

About the Project

Complementary and Alternative Medicine (CAM) is achieving an ever-higher profile in prosperous countries. There is strong evidence of its popularity amongst users (especially in cancer care) although it remains contentious amongst orthodox practitioners. Whilst operating within a very different social, cultural, historical and organizational context, "CAM" is a significant element of (cancer) healthcare in poorer countries. The under-researched nature of CAM is widely recognized, and a trials-based pursuit of an evidence base is increasingly advocated. However, this agenda fails to recognize the importance of generating an understanding of social action in settings where evidence is interpreted. Moreover, much CAM sociology has focused on the "consumer" or the practitioner in isolation.

This project aimed to investigate how CAM is interpreted and utilized in the increasingly important settings of cancer support-groups, charities and networks. It is unique in combining fieldwork in two very different countries - the UK and Pakistan, as well as exploratory work in Australia. The project examined how groups are mediating and interpreting CAM; how this impinges upon professional-lay relations; how patterns of inequality are being influenced; and what effect this has on the management of health and illness.

As a qualitative sociological study, the main methods utilised were in-depth case studies of groups and networks, interviews with participants (i.e. group members, CAM therapists etc.), and document analysis (including material such as information leaflets, publicity material, and reports produced for or by groups). In Pakistan, a large scale quantitative study (n=362) of cancer patients at four main cancer centres in Lahore was utilised in conjunction with in-depth qualitative interviews with selected stakeholders.

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