Making sense of illness: the experiences of users of complementary medicine.

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MAKING SENSE OF ILLNESS: THE EXPERIENCES OF USERS OF COMPLEMENTARY MEDICINE

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ABSTRACT

The present study investigated the experiences of users of complementary and alternative medicine (CAM) using a qualitative approach. In-depth interviews were conducted with 11 frequent users and analysed using interpretative phenomenological analysis (IPA). Results indicated that the patient-practitioner relationship and explanatory frameworks provided by CAM were perceived as important components of the therapeutic process, irrespective of treatment efficacy. CAM served a variety of functions beyond the explicit relief of symptoms by increasing energy and relaxation, facilitating coping and enhancing self/other awareness. It is therefore important that these wider effects are taken into account when evaluating complementary medicine in order to accurately reflect patients' experiences.

Key words: complementary medicine, qualitative, coping, outcomes

INTRODUCTION

The use of complementary and alternative medicine (CAM) has increased dramatically in recent years (Ernst & White, 2000; Zollman & Vickers, 2000). In a recent UK survey, Ernst & White (2000) found that 20% of their sample had used CAM in the previous year and extrapolate from their findings that £1.6 billion is spent annually in the UK on CAM. Explanations for the increasing popularity of CAM can be best understood within the wider context of cultural developments and changes in attitudes towards health and health care provision. Several authors have argued that the rise of CAM in the west reflects the emergence of postmodern values, including disaffection with medical science and greater focus on individual responsibility and consumerism (Baxt, 1991; Shiapush, 1999).

Indeed, this approach appears congruent with studies investigating the factors predicting CAM use. Research typically identifies 'push' and 'pull' factors underlying decisions to consult CAM practitioners (Vincent & Furnham, 1996). Key factors pushing people from orthodox medicine include dissatisfaction with care, concern about the side effects of medicine, and ineffective treatment (Furnham & Bhagrath, 1993; Furnham & Smith, 1988; Vincent & Furnham, 1996). Whilst this is indicative of general concerns with medical treatment, it is also likely to reflect the greater prevalence of CAM use in people with chronic diseases, which are often difficult to treat successfully within the orthodox medical system. In contrast, 'pull' factors refer to those elements attracting people to CAM, such as holistic care, lengthy consultations, and greater autonomy and control over health (Astin, 1998; Furnham & Forey, 1994; Vincent & Furnham, 1996). It seems likely that multiple factors influence initial and subsequent decisions to use complementary therapies and that the relative emphasis of push and pull factors change over time. For example, dissatisfaction with orthodox medicine may be particularly salient in initial decisions to turn to CAM, whilst positive experiences with CAM are more important in subsequent motivations (Luff & Thomas, 2000).

The health beliefs and attitudes of those using complementary therapies have also come under considerable scrutiny. The majority of studies have utilised a quantitative approach in comparing users of various complementary therapies and patients of orthodox medicine in order to provide a profile of those who use complementary medicine. Such studies typically indicate that compared with patients of orthodox medicine, CAM users are more critical of orthodox medicine (Furnham & Bhagrath, 1993; Furnham & Smith, 1988; Vincent & Furnham, 1996), are more likely to have holistic health beliefs (Astin, 1998), and are more concerned with environmental issues and preventative health practices (Furnham, 1994; Furnham & Kirkcaldy, 1996; Kelner & Wellman, 1997), although there are also differences between therapies. These findings are consistent with the argument that complementary therapies are attractive because they are more congruent with patients' philosophical and health beliefs compared with the biomedical perspective (Vincent & Furnham, 1996). Whilst such an approach has proved useful in identifying who uses CAM, it does not capture the complexities of users' motivations and experiences of CAM.

Indeed, there is a dearth of research exploring people's experiences of CAM and the means by which they evaluate CAM treatments. Whilst there is increasing pressure to establish the effectiveness of CAM, most research has continued to adopt an essentially biomedical approach, using randomised controlled trials as the gold standard and focusing on the alleviation or reduction of symptoms, rather than how patients evaluate their treatment. Such an approach employs a top-down framework, based on the efficacy criterion deemed relevant by researchers. However, there is increasing recognition of the importance of understanding the meaning of treatment from the patient's perspective, irrespective of whether it is provided by orthodox or complementary health care. The increasing popularity of CAM despite its considerable cost to consumers, suggests that these therapies may serve an unmet health need (Worth and Richardson, 1995). However, we still know little about how patients themselves evaluate CAM treatments and the extent to which it fulfils these needs. In order to evaluate

the effectiveness of CAM, it is essential that we adopt a bottom-up framework to include the users' perspective.

The results of several qualitative studies suggest that users of CAM experience a range of treatment effects that would not be captured using standard outcome measures (Cassidy, 1998; Gould & McPherson, 2001; Paterson & Britten, in press). Most of these studies have been conducted with either a single therapy or specific groups of patients. For example, three qualitative studies have explored patient outcomes in acupuncture; all reported improvements in symptomatology alongside much broader outcomes which were highly valued by patients. In the US, Cassidy (1998) identified "expanded effects of care", which included physiological coping (e.g. increased energy and relaxation, reduction of medication) and psychosocial coping (e.g. increased self-awareness and well being). Similarly, in a recent longitudinal study in the UK with new users of acupuncture, Paterson and Britten (in press) identified two main types of outcomes: symptom effects and whole person effects, which included changes in personal and social identity. They also evaluated the scope of three outcome measures (EuroQol, COOP-WONCA, and MYMOP2) and found them to be inadequate in evaluating the range of changes experienced by their participants over a six month period, particularly with relation to whole person changes. A third UK study utilised both quantitative and qualitative methods to establish patient perspectives on treatment outcomes (Gould & McPherson, 2001). Although the qualitative findings are not reported in depth, the study found that patients placed greatest value on non-physical changes despite an initial focus on physical problems. The study also highlighted the importance of the therapeutic relationship, including the holistic style of treatment and opportunities for health maintenance.

Whilst there is considerable overlap in the findings of these studies, we do not know the extent to which these findings can be generalised to other complementary therapies. Additionally, further qualitative research is needed to better understand the meaning of complementary health care for patients and the role it plays in wider health and lifestyle

decisions. The present study aims to explore participants' experiences of using complementary medicine and their perceptions of health and illness. It draws on the experiences of users of a range of therapeutic modalities in order to explore underlying similarities across treatments. It particularly focuses on frequent users of CAM in order to provide a richer insight into the meaning and impact of CAM on their lives. The study takes a qualitative and phenomenological approach to understand the meaning of complementary medicine from the patients' perspective. To this end, interpretative phenomenological analysis (IPA) (Smith, 1996) was selected to analyse the data since IPA aims to access the "insiders perspective" on their social world and particularly to elucidate "the subjective perceptual processes" involved when an individual tries to make sense of their experiences.

METHOD

Participants and recruitment

Eleven users of CAM took part in the study, ranging in age from 23 to 66 years; 10 were female. Participants reported using a range of therapies, predominately acupuncture, homeopathy, reflexology, and aromatherapy, and had experience of between one and six complementary therapies. A variety of health problems were reported, although reasons for CAM had changed over time and current reasons for using CAM were primarily for stress reduction and control of chronic health problems.

Recruitment was opportunistic; invitation letters outlining the study were left at several CAM practices in the southwest region of the UK and patients interested in the study were asked to fill out a brief questionnaire if they were willing to be interviewed. Selection criteria included: a) recent use of CAM; b) commitment to using CAM (frequent usage). In order to preserve anonymity, fictional names are used for each participant in the reporting of results.

Procedure

Semi-structured interviews were employed. An interview schedule was developed to provide a structure to the interview whilst allowing the flexibility to respond to issues deemed important to individual participants. The interview schedule was based around the following key areas: reasons for using CAM, history and experiences of using CAM, perceptions of health and illness, and changes arising from CAM use. The development of the schedule was informed by Lofland's (1971) technique of writing down "puzzlements and jottings" which provides a means of generating and structuring questions[1].

Interviews were conducted in participants' homes. They were audio-taped and transcribed verbatim. Prior to the interview, participants' consent was attained to record the interview and all participants' were advised of their ethical rights. Interviews lasted between 30 and 90 minutes.

Qualitative Analysis

Each transcript was analysed using IPA to compile a list of recurring themes (Smith, Jarman, & Osborn, 1999). An idiographic, case study approach to analysis was adopted in the present study. The initial analysis involved repeated readings of each transcript and the recording of initial observations and preliminary interpretations. The second stage involved the identification of emerging themes for each participant, which were coded with key words or phrases that reflected the meaning of the individual's accounts. Each transcript underwent the same analytic process yielding a list of master themes and extracts, which could then be compared across participants. In order to ensure the themes remained grounded in the data, the transcripts were again checked, and marginal themes excluded. Finally, higher order 'super-ordinate' themes were identified which represented participants' perceptions and

[1]This technique involves writing down questions and 'puzzlements' arising from initial explorations, sorting the questions into categories, placing in a logical order, refining questions and elaborating with general probes in preparation for the interview (see Lofland, 1971, p.76).

experiences, both in terms of thematic prevalence (across participants) and thematic salience for individuals. To ensure 'intersubjectivity' (Reason & Rowan, 1981) both authors discussed the rationale underlying each stage of analysis and several transcripts were coded independently by both authors. Additionally, notes were made of observations and reflections throughout the analytic process.

RESULTS

The majority of participants had experience of several different complementary therapies and reported 'dabbling' or shopping around for treatment, consistent with Sharma's (1994) findings. Interestingly, several participants reported prior negative experiences with CAM and yet continued to try other therapies until they were successful. This is consistent with the single participant who reported no improvement in her condition after using acupuncture, but stated that she would 'keep looking for something else'. As might be expected from committed users of CAM, most were highly satisfied with their current treatment modality. The only negative dimension of using CAM for these participants was the prohibitive effect of cost and all recognised that they were fortunate in their ability to afford the treatments.

All patients expressed some dissatisfaction with allopathic medicine but continued to use it alongside complementary therapies, suggesting that users of CAM are pragmatic in their health care decisions (Furnham & Smith, 1988). However, several mentioned that they consulted their GP less frequently since they had been regularly using complementary medicine. This partly reflected an increase in scepticism towards the allopathic approach, but also the maintenance of health through CAM use. Two superordinate themes emerged from the data relating to perceptions of process and perceptions of effect (see Table 1).

Table 1 about here

Perceptions of process

In understanding the mechanisms through which treatment impacted on health outcomes, all participants contrasted their experiences with those in orthodox medicine. Two key components were identified as central to participants' making sense of their illness and treatment: the practitioner-patient relationship and the explanatory frameworks provided by CAM. Additionally these were aspects of treatment that had been found lacking within the orthodox system.

Therapeutic relationship

All participants perceived their relationship with the CAM practitioner as an important component of the therapeutic process, irrespective of the treatment modality. Indeed its therapeutic function was seen as distinct from the efficacy of the treatment itself and several participants made references to its counselling and psychotherapeutic qualities:

> I talk these things through … and just talking about them almost gets them out of my system I'm sure, and then I feel better even without the remedy she is going to give me. (Marie, homeopathy)

The continuity of the relationship, of 'knowing she is there' provided an important source of social support and reassurance as well as being a key factor in participants' long-term commitment to CAM. Central to this relationship was having time and being heard, which was contrasted with participants' experiences of orthodox medicine. The therapeutic qualities of having the opportunity to thoroughly discuss concerns and worries with a practitioner skilled in active listening was apparent in all accounts:

> I don't honestly think that it helped…but I did enjoy going to acupuncture because…it gave me the opportunity to talk about what I was going through…she

> really went into everything you can think of, so you really felt that somebody was listening to you… (Emma, acupuncture)

Participants differed in the emphasis given to various components of the therapeutic relationship; however, common to all was the importance of trust. For some, this trust was engendered by the anonymity or uniqueness of the relationship ('she's anonymous to me, so you feel like you can talk to her'), whereas others valued the relaxed nature of a relationship likened to friendship. In both cases, the relationship facilitated a level of intimacy and openness that was unique to the therapeutic context. Additionally, trust was perceived as crucial in order to facilitate appropriate treatment and to maximise effective outcomes:

> I think with a therapy like that you're going to get the most benefit if you're honest and open with the practitioner, then it's a two way thing really, it's definitely a two way thing. You've got to be able to trust them, otherwise you won't get the benefit. (Jessica, aromatherapy/acupuncture)

A related sub-theme is that of a relationship of equals, frequently expressed in terms of an egalitarian 'two way' relationship. In addition to being a valued aspect of the CAM interaction, this appeared to have influenced participants' expectations about the nature of the professional-patient encounter and the role of the patient in the decision-making process. Thus, several participants commented on how their attitude to allopathic practitioners had changed and how they no longer viewed the doctor as 'the expert'. Instead patients valued playing a more active role in the consultation and in decisions regarding treatment:

> I don't like to be ignorant of what people are doing to me, and I think that stems from going to the homeopath. Because they don't treat you like, you know, they're the expert and you're the patient, they treat you as an equal, and I think that's quite

> important as well, so yeah, I do question you know, what I'm taking, and what the side effects and all that type of stuff. (Clare, homeopathy)

Explanatory frameworks

Complementary medicine provided an important framework for making sense 'of what seems a bit senseless'. Understanding causal mechanisms for illness as well as how to maintain health and wellness was an important theme for all participants. The explanations provided by complementary medicine were viewed as important in aiding participants' ability to deal with their health problems and manage their health.

> And it's not like 'The Answer'. Nothing's 'The Answer', but it can make us feel healthier and better about ourselves. (Tanya, aromatherapy)

Frequently, orthodox medicine had failed to provide adequate explanations for participants' conditions, whereas the holistic approach central to CAM was seen to provide deeper level explanations of health and illness, linking psychological and physical dimensions of health. CAM was therefore perceived as more able to unlock underlying problems rather than simply dealing with symptoms, 'like peeling the layers off an onion'. The concept of links between different levels of the body was a very persistent theme in participants' accounts and was also reflected in perceptions of health as encompassing physical, mental and social well-being. An understanding of causal mechanisms within a holistic framework was closely linked with participants' perceptions of treatment as providing holistic benefits.

> I'm not running general medicine down because obviously a lot of good is done. But sometimes as I say, what's presenting itself is treated and that's not always the cause. And I think with complementary medicine they tend to go into the whole person, and what, you know, what is causing it. (Heidi, aromatherapy)

The explanatory frameworks provided by complementary medicine were often concordant with participants' own models of illness in that they incorporated the social and psychological dimensions of illness. Additionally, most participants had adopted terminology and concepts from CAM, thus expanding their personal explanatory models to include general concepts such as 'energy' and 'balance', and therapy-specific terms such as 'meridians' and 'chi':

> I think what fascinates me about acupuncture is the philosophy that, why that one organ is affected by another and … like in conventional medicine if you've got a gastric ulcer, everything's all concentrated on your stomach, whereas you could go to the acupuncturist like for indigestion, and I mean she'd be putting needles in your foot 'cos of the point the meridians are affecting it. And I find that quite fascinating…and the concept of the seasons affecting the way the body works … (Jessica)

In addition to valuing explanations of health and illness, participants attempted to understand the process of healing and the mechanisms through which CAM operates. Perceptions of CAM as both natural and traditional appeared to provide a rationale for the foundations of CAM. The focus on treatment that is natural reflected both a reaction against the side effects of medical drugs and the adoption of the belief that health involves 'working in harmony with your body'. Two thirds of participants originally turned to complementary medicine because of worries concerning the iatrogenetic effects of orthodox medicine; concern over the side effects of treatment together with their limited effectiveness was a recurring theme in participants' accounts.

> And I think a general awareness as well of, of health or lack of it around us, that makes you think that normal medicine isn't actually creating the solutions that we, that we perhaps at one time thought…And then you find there are other things that medicine's creating problems for people, like with this antibiotics…this feeling that

> it's not all quite right and you want to go back almost, like back to nature type thing. (Marie, homeopathy)

Interestingly, the idea of going 'back to nature' can be related to the recourse to 'tradition' as a way of justifying the mechanisms and effectiveness of CAM. For example, Matthew, a pharmacist, was a strong advocate of acupuncture because:

> It's been going for thousands of years, it's got a history about it, it's tried and tested. Now your modern drugs might work but they've got no background. I mean how many of them get withdrawn after a short period?

In contrast, he felt that homeopathy and 'all these different types of complementary medicines' were 'quack' because they lacked sufficient proof. Clearly then, just as people strive to understand the meaning of illness through causal attributions, they also seek out explanations as to how and why complementary treatments work, drawing on notions of 'natural' and 'tried and tested for thousands of years'.

Another recurring theme regarding the mechanisms of treatment involved the notion of '<u>mind over matter</u>', reflecting the strong emphasis given to the psychological processes underlying treatment effects – 'I reckon if she gave me a smartie I would go out of there thinking it was going to make me better' (Marie). Interestingly, this was perceived as providing evidence of the body's capacity to self-heal and was therefore interpreted as an empowering experience which tapped into one's own personal healing capacity and reduced dependence on external or unnatural factors.

> As I say you don't know if it's in the mind, or, but then if it's the mind, it's making the mind heal you so it doesn't really matter, you know…I think a lot of it is having faith in what they are doing. (Heidi, reflexology/aromatherapy)

At the same time, the difficulty of delineating the exact mechanisms of treatment effectiveness were acknowledged, although this was not seen as problematic providing positive outcomes were subjectively experienced:

> A lot of it is how you accept the treatment in your mind yourself as well, because you heal yourself rather than them healing you. So, in some ways you don't know whether it's just that you take a look at your own circumstances and your lifestyle and you do something about it yourself, or whether it is the actual reflexology. But I wouldn't keep going and paying the money if I didn't think it was doing me some good. (Katrina)

Whilst accepting the psychological component underlying treatment, even the strongest advocates of CAM described ways in which they undertook a search for legitimacy to test the efficacy and validity of treatment. Several methods of credibility checking were employed, such as monitoring bodily changes, seeking out anecdotal evidence, and withholding information. Obviously people sought evidence from their own experience of treatment effects but also those of family and friends which further substantiated their own conviction in CAM. The efficacy of CAM was also frequently compared with that of orthodox medicine, particularly where the latter had been unsuccessful:

> And I've got friends who've had acupuncture for migraines and hayfever and those sorts of things, whereas the tablets that they've been given for years don't do anything, so, there must be some reason that natural remedies work better than what you get given from the G.P. (Katrina, reflexology)

In the case of homeopathy, several participants also mentioned its success with animals, which provided them with further evidence that the treatment itself was having a direct effect as opposed to non-specific or psychological factors:

> I mean I've seen it work on pets as well, so it can't be that bad (laughs), so it's got to work. So, a rabbit doesn't know what it's taking on its lettuce leaf… (Abigail, homeopathy)

Additionally, most participants appeared to undergo a process of testing their practitioners to assess their knowledge and treatment effectiveness. This involved withholding diagnostic information or monitoring physical changes during or immediately after treatment:

> But the thing is, I don't tell her (what's wrong) because I want to know what she can feel. (Lucy, reflexology)

Perceptions of effect

Treatment was seen to impact on several dimensions of individuals' lives beyond the relief of symptoms. Consistent with previous findings, participants were initially motivated to seek out CAM to address specific symptoms or health problems but their motivations changed over time as they experienced the wider effects of treatment (Gould & McPherson, 2001). In some cases this entailed an improvement in secondary health problems ('that's not what I went for, that was, you know, that was a spin off'), whilst others described a change of focus to health and wellness rather than illness. Four sub-themes emerged from the analysis, incorporating physiological changes (symptom relief and energy & relaxation) and psychosocial developments (coping and relationship to self and others).

Symptom relief

All but one of the participants reported an improvement in either primary or secondary symptoms. In some cases, treatment led to a concomitant decrease in the use of medication, particularly for painful conditions. One participant described the pain relief following his initial acupuncture treatment as 'like a miracle' whilst also noting from blood glucose

readings that his diabetes had ‘levelled off’, despite seeking treatment purely for pain relief. Seeking homeopathic treatment for menopausal symptoms, Marie was similarly surprised by the rapidity of treatment effects:

> I was having like hot flushes every hour, on the hour it felt like…I came away with this little pill thing and um took that, and honestly, it was lachesis the one she gave me, and my hot flushes stopped overnight, I couldn’t believe it.

Most participants noted a temporal dimension to their symptom alleviation although different patterns emerged. For some, initial treatments produced the most pronounced effects which levelled out over time, whereas for others treatment effects were more gradual or variable.

> It does vary in the effect of it, really, I must say. Sometimes it, you know, helps for a week and other times it’s not so helpful. (Jessica, acupuncture)

Although no negative treatment effects were noted, several participants discussed how ‘things usually get worse before they get better’ both in terms of physical and psychological symptoms. This was accepted as part of the treatment process and indeed was used as an indicator that the treatment was working effectively.

Energy and Relaxation

Beyond treating specific health complaints, complementary medicine was frequently perceived as increasing energy levels and giving a “boost”. This enhanced physical and social functioning whilst also impacting on overall well-being.

> If you feel happy with yourself and got enough energy, I think that’s quite important really. And I think that’s what homeopathy gives me, gives me energy, gives me get up and go. (Clare)

Another secondary outcome of treatment was increased levels of relaxation. This was particularly pertinent to those using physical manipulation therapies such as massage and reflexology. In addition to physical relaxation and its consequences, such as improved sleep, these participants related their physical experience to mental well-being, both in the short and long-term:

> I think that's the main thing, this complete and utter relaxation…all your things that you're worried about, just kind of fade away really, so it is, it's just complete physical and mental relaxation. (Heidi, reflexology)

Participants' accounts of treatment thus clearly reflect the wider explanatory concept of holism, whereby physical changes in energy and relaxation are intimately related to more subtle changes at a mental or emotional level. This is illustrated in Tanya's account of her experience with massage therapy:

> Physically I feel like it has an effect because it's working on a physical level toning and releasing toxins or whatever. In terms of my brain it slows my brain down, so I can relax a bit, and as I said maybe sleep better or something like that. Often on an emotional level I'll feel like more in touch with my emotions afterwards and it might release something, I might cry, or somehow I might feel just more in touch with my emotions.

Coping

An important function of treatment was to provide additional means of coping, both with specific health problems and with wider life stressors. Interference with lifestyle and social responsibilities was a major reason for seeking out complementary health care, and consequently, developing strategies to control the physical manifestations and consequences

of health problems was considered an important treatment outcome. The development of coping strategies emerged from three key sources: the success of the treatment itself, communication with the practitioner, and expanded ways of understanding health.

Belief in the effectiveness of treatment enabled participants' to take control over their health, which also helped to reduce illness-related anxiety. This was particularly evident for conditions that were socially debilitating such as irritable bowel syndrome and visible skin complaints. In such cases, treatment enabled individuals to resume social duties and gave a 'new lease of life'.

> It's like when I was at school, it (psoriasis) used to be like dandruff…and it used to get me down because I mean, I was always frightened people would pick on me…so it's nice to be able to rely on something that works. (Abigail, homeopathy)

The reconceptualisation of health problems and general outlook was a significant coping mechanism for some participants. Stress was frequently mentioned as either a primary problem or as an aggravating factor for chronic conditions. Finding new ways to deal with stress and its consequences was therefore an important coping mechanism. This was linked with the development of coherent frameworks for understanding health and illness which facilitated the acceptance of both illness and wider stressors. Most frequently reconceptualisation involved 'seeing things as challenges rather than real difficulties' which had an impact both on ability to cope and overall mental outlook and well-being.

> I looked at things in a sort of a like more positive light… I was sunnier in my sort of inner outlook and that, it was brilliant. (Clare, homeopathy)

Consistent with previous findings (Cassidy, 1998; Paterson & Britten, in press), restoring physical and psychosocial balance was considered an important treatment outcome. This

relates to the adoption of CAM metaphors of healing (e.g. 'to get the balance back') and also to the understanding of treatment as holistic in approach and outcome:

> What she treats is the not just the physical symptoms, but the emotional, the spiritual, the mental as well as the physical, and so…she seems to keep the whole of me in balance, and I go out of balance sometimes particularly, you know, with my work…and the only way I can put it is that when I see her, whatever she gives me seems to restore that balance. And when you um do get ill…you seem to get over things quicker and they don't seem to knock you quite as much as they used to. (Marie, homeopathy)

A fourth key coping mechanism was an increased focus on health maintenance. Although a concern with positive health may describe the typical CAM user profile (Furnham & Kircaldy, 1996), most participants discussed how their perceptions of health had changed whilst using complementary medicine, and how this had impacted on their health behaviours. A common theme was a concern with 'topping up' one's health, through regular consultation with the CAM practitioner, by learning to be more "in tune" with one's body and needs, and by adopting a healthier lifestyle through self-treatment, diet and relaxation. Many described how they adopted elements of their therapy, for example by using aromatherapy oils or massaging pressure points, in addition to making lifestyle changes to reduce stress and maximise fitness and wellbeing. Whilst concern with lifestyle and health maintenance was partly a result of treatment, it was also a motivating factor for continued use of CAM since more weight was given to environmental and personal antecedents of health and illness.

> You've got to listen to what your body's telling you, and if, if you're continually working against the treatments, you know, then you can't expect it to work. (Jessica, aromatherapy/acupuncture)

Making lifestyle changes was also related to a greater sense of responsibility over one's health, an attitude iterated by the majority of participants. Whilst this appeared to be something that is developed over time with continued familiarity and involvement with CAM, it is also a major motivation for initially deciding to seek out complementary medicine (Furnham & Forey, 1994). It is apparent that participants in the present study felt empowered by their experiences with CAM to take responsibility for their health:

> It gives you a whole new outlook on looking after yourself, rather than letting somebody else look after you. (Marie, homeopathy)

Relationship to self and others

A subsection of participants reported changes in both the way they viewed themselves and in how they related to others, particularly in terms of enhanced self/other awareness. These changes in the conceptualisation of self and others were perceived as having ramifications for health and beyond, impacting on participants' relationships, lifestyles and professional lives. Changes in self-identity were associated with increased self-acceptance and self-worth, often characterised by recognition of the need to pay greater attention to personal needs. This attention to the self was perceived as empowering both in changing self-perceptions and by facilitating a sense of control over life circumstances.

> I think it's made me a bit more tolerant of myself, which is the main thing, because I was my own worse critic really, always expecting myself to do everything. And it makes you realise that part of you looking after yourself is not being all things to all people, you know that um, you have to save a little bit for yourself. (Marie, homeopathy)

It was also recognised that such changes in mental attitude had an impact on health status though reducing stress and preventing illness in the longer term. Through changing self-

perceptions, participants also adapted their lifestyle to incorporate greater self-reflection and personal space.

> You realise the value of taking some time out for yourself and realise that that in itself will probably, you know, alleviate the stress and pain. (Jessica, aromatherapy)

In addition to changes in self-identity, several participants felt that using CAM had led to changes in their perceptions of others, which had enhanced their social and professional relationships. In the main, this similarly reflected changes in acceptance and tolerance, which were extended to include the actions of others. In particular, participants discussed how their interest in the underlying meaning of people's actions facilitated a less judgemental attitude.

> I've accepted, you know, myself much better and it's made me more accepting of other people as well. And I sometimes look for reasons why people are the way they are. My husband can be quite difficult sometimes and before I used to sort of, rise to it and we used to have full-blown arguments. But now I suppose I try to understand him a bit better…so I think it's made me easier to live with as well. (Katrina, reflexology)

As a nurse, Jessica recognised the impact of aromatherapy on her professional capacity by making her more attuned to the needs of others:

> I think I'm more aware, more open to um, the need for the listening part of the job, that, you know, how it is important for people to be able to have the time to talk and express their fears, hopes and fears.

Although these changes to personal perceptions were not evident in all discourses, they reveal the profound way in which treatments were perceived to impact on both the personal world of the individual and their wider social relations.

DISCUSSION

The present study explored people's perceptions of health and illness within the context of their experiences of using complementary medicine. It was found that orthodox medicine provided a comparative framework against which people's experiences with complementary therapies were contrasted. Participants' perceptions of the key processes inherent in treatment were congruent with research in both complementary and orthodox medicine (e.g. Johannessen, 1996; Luff & Thomas, 2000; Ong, de Haes, Hoos & Lammes, 1995) with emphasis given to the patient-practitioner relationship and a coherent explanatory framework for understanding illness and its consequences. Both were perceived as central components of the healing process in addition to providing benefits for wider health. Outcomes of care were multifaceted, incorporating physiological changes and wider psychosocial benefits that reflected both perceptual and behavioural changes.

Previous theorists have suggested that the rise in the popularity of CAM reflects the predominance of postmodern values and attitudes (Bakx, 1991; Siahpush, 1999). Several key beliefs associated with this philosophical orientation were evident in the current discourses: nature as benevolent, holism, the rejection of authority (medical paternalism), consumerism, and individual responsibility for health (Coward, 1989; Siahpush, 1999). However, there was little evidence of an 'anti-science' attitude; rather than rejecting the scientific approach, participants recognised the importance of personal legitimacy in making treatment choices (Haug & Lavin, 1983). By using both orthodox and complementary medicine and 'shopping around' for treatments, participants adopted a consumerist approach to meet their health care needs (Sharma, 1994). Initial decisions to use CAM were primarily pragmatic and reflected dissatisfaction with orthodox medical care and concerns about the costs of science in terms of

treatment side-effects and a lack of attention to the whole body consequences of illness. Over time, greater attention was given to the notion of individual responsibility for health and the maintenance of physical and psychological well-being, suggesting the emergence of an 'alternative therapy ideology' (Pawluch, Cain & Gillet, 1994) with continued use of CAM.

The therapeutic relationship between practitioner and patient was seen to augment direct treatment effects in several ways. Firstly, its psychotherapeutic qualities were recognised as important in reducing anxieties and facilitating greater acceptance, both in terms of health issues and self identity. Having the time to discuss concerns within the context of an open and trusting relationship was central to this process (Gould & MacPherson, 2001; Johanessen, 1996; Paterson, under review). Secondly, the supportive nature of the relationship enabled individuals to manage illness and other stressors more effectively within the context of their everyday lives. Thirdly, the egalitarian nature of the relationship challenged traditional notions of power between health professionals and patients and empowered individuals to assume greater responsibility for their health. Indeed, the nature of the practitioner-patient relationship in CAM appears to exemplify the participatory model of communication and decision making currently so in vogue in health care (Towle & Godolphin, 1999).

Additionally, the explanatory models provided by CAM helped to give meaning to the individual's illness experiences and to better understand the positive dimension of health. The holistic approach offered by CAM was key to providing an integrative framework to understanding the causal mechanisms underlying illness and has been found in previous studies to provide a major attraction to using CAM (Coward, 1989; Sharma, 1995). Whilst it might be expected that system approaches which provide an underlying philosophy of action such as acupuncture and homeopathy would provide more unifying explanatory frameworks, the present study found no differences between therapeutic approaches. The holistic approach offered by all modalities was perceived as central to understanding and important in distinguishing CAM from orthodox medicine. Thus, CAM appears to offer a more congruent

biopsychosocial framework to incorporate lay peoples beliefs about health and illness (Astin, 1998). The association between cohesive causal explanations and adaptation to illness has long been established (Taylor, Lichtman, & Wood, 1984; Turnquist, Harvey, & Anderson, 1988). Additionally, the individualistic nature of treatment provides explanations and solutions which encourage functional adaptation for each individual (Johannssen, 1996).

In addition to making sense of illness, participants' accounts demonstrated the ways in which they understood and evaluated the treatment itself. Whereas CAM was viewed as natural and therefore safe through working in harmony with the body, orthodox medicine was perceived as harmful in causing side-effects and immunity with prolonged use. This appears to reflect the growing concern about the iatrogenic effects of modern medicine together with a belief that natural remedies are safer and therefore more desirable (Horne, 1998; Sharma, 1995). Although these beliefs were supported by participants' personal experiences, this clearly raises wider questions regarding the accuracy of public perceptions of the safety of both orthodox and complementary medicines. Participants were not however, unquestioning about the efficacy of CAM. Rather they demonstrated 'smart consumerism' (Kelner & Welman, 1997) in their health care decisions whilst implementing various mechanisms to evaluate treatment effects, ranging from anecdotal evidence to biological markers of change (Thorne, Paterson, Russell, & Schultz, 2002). Additionally, participants recognised and valued the psychological component of treatment perceiving it as part of the 'treatment package'.

The indivisibility of non-specific and direct treatment effects is reflected in participants' evaluation of therapeutic outcomes, which demonstrate the inherent interaction between physical, psychological and social outcomes. Overall, treatment was perceived as having a long-term impact on several different levels of patients' lives, beyond the reduction of primary and secondary symptoms. These findings are consistent with the 'expanded effects of care' described by previous research with acupuncture patients (Cassidy, 1998; Gould & McPherson, 2001; Paterson & Britten, in press). Whilst individuals may initially seek

complementary health care to treat a specific, often chronic problem, over time the focus widens to include general feelings of wellbeing and illness prevention (Gould & McPherson, 2001; Thorne et al., 2002). Indeed, the multifaceted nature of chronic illness means that it potentially impacts on all levels of an individual's life and requires considerable adaptation, including the development of new meanings of the self (Bury, 1982; Charmaz, 1983). CAM appears to offer the potential for learning adaptive coping skills that may be applied to the challenges posed both by illness and wider life stressors. Coping behaviour is typically understood in terms of primary and secondary appraisal, in which the individual evaluates the threat and considers the availability of coping resources (Lazarus & Folkman, 1984). The strategies reported by participants in the present study work towards adaptation on both levels, through reappraisal (e.g. reconceptualisation) and expansion of coping resources (e.g. support and increased energy).

The value placed on a range of health related outcomes supports previous qualitative research and highlights the importance of assessing these broader changes when evaluating complementary medicine in order to accurately reflect patients' experiences. Thus, a more value orientated approach must necessarily incorporate patients' own criteria of effectiveness. Clearly the measurement of 'expanded effects of care' presents a challenge, particularly with regard to highly individualised changes such as self identity. In a comparison of several patient centred measures, Paterson & Britten (in press) found that they were limited in their capacity to record the diversity of experience reported by participants. The current study suggests the importance of assessing changes in coping as an important mediating factor in long-term health. Choice of outcome measures may also need to reflect individual illness profiles; for example, improvements in energy may be particularly relevant to debilitating disorders (Thorne et al, 2002).

The range of outcomes is also indicative of CAM as a complex intervention involving several components (Campbell, Fitzpatrick, Haines et al, 2000; Paterson, under review). Both the

present study and previous research indicate the importance of the therapeutic relationship in this process and the necessity of adequate time to provide individualised diagnosis and treatment (Luff & Thomas, 2000, Johannessen, 1996). This therefore has implications for the nature of CAM provision in the future, particularly should CAM be integrated more fully within the orthodox medical system, with resultant pressures on time and resources. Any erosion in consultation time could have an impact on quality of care and patient valued outcomes. Further research is needed to explore the impact of context on treatment outcomes and patient satisfaction, particularly between private and NHS provision of CAM.

The methodological limitations of the current study should be acknowledged. The findings reflect the perceptions and experiences of a small number of CAM users at a single point in time. In particular, the present study chose to focus on those committed to using CAM as part of their regular health care, as opposed to new or infrequent users of CAM. It is clearly important to distinguish between these different groups of users since their motivations and experiences of using CAM are likely to differ. The opportunistic sample of the present study is also likely to over represent those with favourable experiences of CAM and it was heavily biased towards female perspectives. Whilst this reflects the actual gender bias in CAM usage, it is important that future research investigates the experiences of a wider social representation of users, including those accessing CAM through the NHS.

In conclusion, the current study captures the wide-ranging impact of complementary medicine on users lives. Whilst traditional outcomes of symptom relief and cure were widely reported by participants, more subtle aspects of change were also central to participants' experiences and further informed the way in which they evaluated treatment effectiveness. This in-depth exploratory study reveals the processes through which CAM helps people to make sense of and adapt to illness but also raises broader issues regarding the provision of care and evaluation of CAM. The findings support wider research into the value of providing individualised patient centred care to encourage patient involvement and facilitate the

successful management of chronic illness (Von Korff, Glasgow, & Sharpe, 2002). It also suggests the value of employing qualitative methods in conjunction with quantitative outcome assessment to identify the mechanisms and effects of treatment from the patients' perspective. This will ensure that evaluation of CAM is both clinically and value-driven.

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Table 1: Summary of core and sub-themes arising from participants' accounts

Perceptions of process

Therapeutic relationship

- Having time and being heard
- Trust
- A relationship of equals

Explanatory frameworks

- A holistic approach
- Natural and traditional
- Mind over matter
- Search for legitimacy

Perceptions of effect

Symptom relief

Energy and relaxation

Coping

- Control
- Reconceptualisation
- Balance
- Health maintenance

Relationship to self and others

- Self identity
- Perceptions of others