

# **Mediating Trust in Complementary and Alternative Medicine Treatment Decision Making**

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## **ABSTRACT**

Complementary and alternative medicine (CAM) comprises of a number of clinically and theoretically distinct therapies and practices, many becoming increasingly incorporated into the health care regimens of Australians. This paper explores the accounts of 16 regular CAM users to explore trust in CAM treatment decision-making. Self-reliant in their health information seeking and experimental in their use of health treatment, the CAM users in this study exemplify the self-reflexive health consumer of late modernity. This paper shows that trust derives from confidence in the CAM practitioner, and also relates to culturally inscribed beliefs around pain and pleasure. Utilising the sociological theories of Giddens and Luhmann, the argument in this paper is that different boundaries and thresholds of trust are enacted in relation to the use of CAM and biomedical treatments.

## **INTRODUCTION**

Several cross-sectional population health surveys show a significant increase globally in CAM use since the early 1990s and in Australia, between 52 percent (MacLennan, Myers et al., 2006)<sup>1</sup> and 69 percent (Xue, Zhang et al., 2007) of the Australian adult population have used CAM in the last 12 months. There is also a corresponding increase in the use of CAM practitioners (also termed 'therapists'), and CAM has clearly become a significant component of the health care regime of many Australians. Why do Australians engage with treatments which have no scientific evidence base? What underlies the trust in CAM treatment?

Medical anthropologists (Bakx, 1991:33; Cant & Sharma, 1999:25) have theorised that biomedicine has culturally distanced itself from its patients, and that the public has generally lost trust in biomedical treatments, furthermore there is increased publicity over the adverse effects of compound pharmaceutical medicines and invasive surgical treatment, and this produces generalised public anxiety over the use of biomedical treatments. While social science literature (see Baarts & Kyrger Pedersen, 2009:720; Lupton, 1997) points to dissatisfaction with the medical encounter and the health outcomes of orthodox

biomedicine, there is also evidence that CAM is not necessarily a rejection of biomedicine, rather it is used as part of a suite of health treatments (Adams & Sibbritt et al., 2009). From a sociological perspective, the interest is in how CAM users work with these tensions between CAM and biomedicine, and the mediation of trust in expert and lay knowledge. The mediation of trust in these contexts is not well understood, and there are very few studies exploring trust in CAM from a sociological perspective. Through exploring how CAM users mediate trust between the expert knowledge claims of biomedical and CAM practitioners this paper makes an important contribution to the sociology of CAM.

## THEORETICAL FRAMEWORK

Health social science literature has tended to treat trust as a variable, rather than a theoretical construct. Among health sociologists there is a body of work emerging which engages with trust theoretically, and draws on theories of trust to explain how trust in the health system is reproduced in social and environmental contexts (see Brownlie & Howson, 2005; Meyer & Ward et al., 2008). The prominent trust theorists cited in these studies are Giddens (1991; 1995) and Luhmann (1979; 2000) both theorising trust as mediated between institutional and interpersonal contexts. Both theorists see trust as conceptually related to faith and confidence. For Giddens (1995:34) it is confidence which provides the link between trust and faith, trust being: ‘confidence in the reliability of a person or system, regarding a given set of outcomes or events, where that confidence expresses a faith in the probity or love of another, or in the correctness of abstract principle (technical knowledge)’. For Giddens, trust is seen to emerge in interaction with the representatives or ‘access points’ to expert systems (Brownlie & Howson, 2005:222). Accordingly when dealing with expert systems such as CAM, trusting in practitioners who are representatives of CAM systems means exercising a ‘leap of faith’ in their institutional knowledge.

Luhmann (2000:95-96) argues that trust develops not just in interaction, but in familiar contexts, and argues that changes to these contexts will impact on the development of trust. For example, the media represents the familiar, and a means of entering an unfamiliar world through the familiar (Brownlie & Howson, 2005). At the same time we introduce into the unfamiliar *symbols* from the familiar lifeworld, which become forms of self-reference, and serve the basis of our meaning making of knowledge. Luhmann (1979, p.73) also argues that experience is important to the expression of trust: ‘for the distribution over time of the various attitudes (familiarity, trust, and distrust) the existence of *thresholds* [original italics] is important’. For Luhmann the thresholds are a form of artificial discontinuity which depends on the setting of boundaries, and these boundaries simplify the complexity of trust. Through exercising these boundaries, trust can readily become distrust, which in itself is reinforced and endorsed in social interaction.

The present study explores trust in CAM use through the exploring the enactment of boundaries around acceptable CAM treatment and practices, also in assessing how familiarity and faith in a practitioner contribute to trust in CAM. The interest in exploring trust in CAM is that CAM largely represents systems and practices with little or no scientific evidence base, as such trust is expected to be premised on different contexts to trust in biomedical approaches.

## METHODOLOGY

This paper draws on the accounts of 16 regular CAM users (13 females and three males, aged from late twenties to early sixties) who were interviewed in-depth, with 'regular' defined as using CAM for longer than five years, and/or using two or more CAM therapies over three years and at least three times a year. Based on these interviews a constructivist grounded theory (CGT) methodology was used to produce an interpretative, social constructionist account of trust in CAM, and support a full exploration of the boundaries supporting trusting relations with both CAM and biomedical providers. CAM users were recruited through CAM practitioners in the Sydney metropolitan, Hunter, North Coast and Central Coast regions of New South Wales (NSW). The interviewees are also seen to be representative of other CAM users (see Adams, Sibbritt et al., 2003; MacLennan, Myers et al., 2006) in that the majority are aged between 30 and 55 years, are female, well educated and professionally employed.

## FINDINGS

CAM is found to be used regularly for its derivative benefits such as increased energy and vitality, feelings of relaxation and calm. As supported in other social science studies of CAM use (Baarts & Kryger Pedersen, 2009; Cartwright & Torr, 2005) derivative benefits including an experience of flow and other sensory pleasures are motivations for continuing CAM treatment, even when a treatment is not curative. To this end, at least three female CAM users had used natural fertility treatments for reproductive health and pregnancy. Now a mother of two, Lucy initially fell pregnancy *after* having natural fertility treatment noting 'it [naturopathy] didn't help me to get pregnant and stay pregnant, but it helped me get a lot healthier'. Annie also continued with natural fertility treatment for its intrinsic rewards, even though she also failed to fall pregnant from natural fertility treatment:

It was important to me that the experience of trying to conceive was positive. When I went through the conventional channels I felt vulnerable, very teary, I felt out of control ... With CAM, the people were supportive, no question was too stupid. They were very positive, very honest. They included my partner in all of the treatment. The whole experience, even though it took 14 months, I felt good about it. Even if I didn't conceive I was more reconciled. (Annie, 43 years)

CAM users like Annie and Lucy are actively engaged in constructing boundaries around health care treatment. In this account Annie resists the disembodied, reductionist approach of assisted reproductive medicine (Howson, 2004:46) and simultaneously embraces natural fertility treatment. Elsewhere in Annie's account are evident tensions between her faith in natural fertility based on anecdotal reports of other women's success, and trust in the ART 'success rates':

I didn't necessarily grow up in that sort of environment where everything needed to be explained. And when you have that sort of ...black and white personality actions and words and all that sort of stuff is important to me, it's the whole mystery of life I think. I think that's why, and I still don't necessarily need to have things proved to me. (Annie, 43 years)

Here, Annie explains how her Christian beliefs support faith in CAM treatment, and she is simultaneously sceptical of scientific evidence. Although biomedical practices privilege scientific evidence, some forms of CAM are seen to privilege anecdotal forms of evidence, and this is reflected in accounts from CAM users such as Annie who see intuition and experience as constituting a legitimate evidence base for CAM. Despite the scepticism over scientific 'evidence' the CAM users do not reject biomedical practice, and their episodic use of multiple treatments is congruent with Bauman's (2007) theory of liquid modernity, in which time is pointillist, and marked by discontinuities, rather than a series of linear treatment approaches. For CAM users in the study, the discontinuity is reflected in an experimental approach to treatment use. Such ad hoc use of treatment reflects Giddens (1995) proposition that modern consumers engage in complex assessments of the relevance of multiple knowledge claims including those of expert systems, and apply these to their individual contexts.

Although CAM users oscillate between CAM and biomedical treatment, there are differing thresholds for developing trust in CAM and biomedical treatments, and these partly reflect the differing notions of 'evidence'. Another area of boundary construction is around the toleration of pain and physical discomfort in treatment. CAM user accounts show preparedness to tolerate pain if a biomedical treatment is seen as necessary to health. In describing a dental visit to remove an abscess, Amy (47 years) notes 'Oh, there were times of pain, sure. But I'd prefer to handle the pain than have that stuff [anaesthetic] put in my body. I feel sick after that, I react to that, often I don't want it, I just don't want it'. Despite an overall resistance to biomedical intervention, Amy still found the treatment necessary for health. By contrast, CAM users not only resist pain in CAM treatment, but cease treatment when pain is experienced, and particularly in acupuncture and musculo-skeletal treatments. For example Bella recalls the 'torture' of acupuncture needles, and of having a 'machine on me and they made me black out with needles'. Jan similarly found acupuncture pain unacceptable, noting 'I don't care how good it is, I don't want this pain'. Jan's TCM practitioner integrates into acupuncture practice expert knowledge claims which support the centrality of pain to healing. For Jan the interaction creates tension between her

culturally inscribed belief in pain avoidance, accompanied by a belief that the practitioner minimise pain and her trust in the expertise of the practitioner. This sentiment is echoed by CAM users such as Ben, who describes as ‘incompetent’ a practitioner who inflicts pain. Inflicting pain in treatment is also seen as incongruent with the concept of a ‘healer’:

I’ve been to a physio, osteopath in [location], he was awful OK. And he twisted my leg and back and hurt me quite a bit and trying to get it rid, he never did but in the attempt, you know, he just unsettled me so much that halfway home I just burst out in tears...I never went back to him, he didn’t have what is needed. He wasn’t a healer. You see, to be a healer you have to have the connection with the person because you’ve got to help me get well, that’s your job. If you don’t want that then you shouldn’t be in the job, you know. (Fifi, 47 years)

What these accounts reveal are pain beliefs (Bendelow, 1993:273) inscribed within a social-cultural narrative of pain avoidance (Illich, 1995/1975). These beliefs underlie the establishment of a personal boundary around acceptable CAM treatment. Boundaries developed from pain beliefs suggest there are differing thresholds of trust between CAM and biomedical practices, biomedical treatment a health care necessity and CAM as a non-essential health care choice.

CAM users rely heavily on their practitioners for expertise and advice, as expert knowledge claims for CAM systems are not prominent in public health discourse. This makes CAM practices less familiar to the user than biomedical treatments, and when an unfamiliar practice such as osteopathy or acupuncture is painful, no reference point exists for understanding the pain. This enforces a boundary in which experiences like pain are not tolerated in unfamiliar contexts (see Luhmann, 1979; 2000). The only reference point to mediate trust in CAM practice is a practitioner, whose represents the access point (Giddens, 1995) for the expert knowledge of CAM. CAM user accounts also show if a practitioner is not relatable, then trust in the CAM system more readily turns to distrust. Consider the following dialogue with Corinne, in which the basis for trust in the Traditional Chinese medicine (TCM) is about the practitioner interaction:

Corinne: I was taking those before, and that was a similar thing, I had too much chi or something. Maybe it was a language thing or it wasn’t like a thorough consultation, I just trusted he knew what he was doing with these disgusting herbs. I guess I needed something more than that...I didn’t really know that he understood me, and I didn’t really understand him.

Interviewer: Because of the language?

Corinne: I think so. .... He was like real old traditional Chinese medicine which I wanted to give a go at, but you know, it was just a bit difficult for me because I didn’t really know that he understood what I was saying...so I didn’t feel that confident with it all. (Corinne, 35 years)

Corinne’s account reveals a multiplicity of meanings around CAM use, notwithstanding the exoticisation of herbs and the TCM practice. Corinne’s account suggests she requires rapport with the practitioner to

maintain CAM use, and that it is this confidence in the practitioner which actually stimulates trust in the treatment. Similarly for Fifi, the healer is relatable, and their very presence can produce derivative benefits. In this sense CAM therapists occupy the position of ‘miracle worker’ that doctors once held (Illich, 1995:159), and this is supported in Barnum’s (1999:221) study which found healing is concerned with the whole person, bringing a person into a relationship with themselves emotionally, spiritually and physically, and encompasses both being cured and not being cured of illness. Trust develops when the ‘healer’ produces a familiar state of wellness, and restores the user to a familiar, pain-free existence (Frank, 2004:21). This aligns with Giddens (1995) notion that trust involves confidence in someone’s knowledge.

## CONCLUSION

Using health services in a pluralistic fashion, being discerning in their choice of health service and having high levels of health literacy, and the participants typify the late modern, reflexive health consumer (Giddens, 1991). Despite real concerns over health risk the regular CAM users in this study continue using biomedical treatments for curing specific health conditions. In this pluralistic health context, the CAM users need to mediate between differing forms of evidence for CAM therapies, and this paper has shown how they develop and exercise boundaries around acceptable healthcare practice, and these boundaries form thresholds of trust in CAM. CAM users cease treatment when pain is experienced, and question their trust in a CAM treatment when the practitioner is not relatable.

If CAM users are so able to embrace leap of faith in CAM treatments from which they expect no clinical outcome, yet so willing to reject a treatment when pain is involved, or when the practitioner is not relatable, then what does this ultimately suggest? CAM practices in literature are generally conceptualised as a health related experience. However this paper shows that when examined in a broader context for some CAM practices, there are conceptual and empirical connections not only with health, but also with spirituality and healing, leisure, and a generalised sense of well-being. What emerges is the possibility that some forms of CAM are used in a more choice-driven, and leisure oriented fashion than are biomedical treatments, and that this is reinforced by differing thresholds of trust between CAM and biomedical approaches. How this relates to trust in CAM is an issue well worth exploring in future studies.

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<sup>i</sup> MacLennan's definition includes over the counter medicines such as vitamins, mineral supplements, soy products, aromatherapy oils, and others, as well as herbal, Chinese and homeopathic medicines. Excluded were calcium, iron or vitamins prescribed by a medical practitioner. Although MacLennan's surveys were conducted in South Australia only, the findings were largely used as a proxy for national prevalence estimates until more recent surveys were published.