

# REFLEXIVE PRACTICE: WAYS OF USING COMPLEMENTARY MEDICINE BY PEOPLE LIVING WITH HIV/AIDS

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## ABOUT THE PROJECT:

Over half of respondents to five consecutive surveys of people living with HIV/AIDS (PLWHA) in Australia reported using at least one form of complementary medicine (CM), including vitamin and mineral supplements, herbal medicines, traditional Chinese medicine and massage [1-4]. CM users were as likely as non-users to be using antiretroviral treatments (ARV) for HIV. Research conducted in other western countries has reported similar patterns of CM use among PLWHA [5-12].

Given the high rate of CM use amongst PLWHA it is important to understand the meanings of these practices for CM users and how people make decisions to use them alongside ARV. The current popularity of CM practices in Western countries has been attributed to a post-modern scepticism of biomedicine and a loss of status of doctors [13]. Other suggested reasons for the current popularity of CM practices include the rise in consumer culture, the growing popularity of preventative health, the ideology of individual responsibility for health and the influence of the internet on how people seek information about health [14-19]. The fact that many PLWHA are using CM alongside ARV suggests that decision making and beliefs around health and illness are complex.

This project explored how a group of PLWHA made decisions about managing their health. It focussed on interactions between PLWHA and health care practitioners, as well as their experiences with and attitudes towards, CM and biomedicine.

## WHO PARTICIPATED?

In-depth, semi-structured interviews were conducted with 18 PLWHA who lived in or around Melbourne, Australia in 2005. Participants were recruited through an existing database of respondents to the HIV Futures 4 survey. Twelve men and 6 women ranging in age from 33 to 65 years participated in the study. All except one had used ARV for HIV at some time and all were currently using some kind of CM. The types of CM practices used included chiropractic, acupuncture, massage, naturopathy, vitamin and mineral supplements, herbal medicine, traditional Chinese medicine and shiatsu.

## RESEARCH FINDINGS

### WHY WERE PEOPLE USING CM?

CMs were most often used for reasons relating to experiences of using ARV, such as to:

- Minimise the impact of treatment side effects
- Strengthen the body to cope with HIV
- Increase control over the substances they were putting into their bodies
- Avoid using additional pharmaceutical medicines for side effects and co-morbidities;
- As part of a long term health maintenance strategy
- As part of a holistic approach to managing chronic illness

### LIVING WITH CHRONIC ILLNESS

The ways that participants used CM were not fixed and had changed over time living with HIV. Four participants who had used CM extensively before being diagnosed with HIV had initially avoided taking ARV. However over time all had come to a decision that they needed to take ARV to stay alive, although they did not necessarily view their use of these treatments as permanent, rather as this man commented, that the roles for both ARV and CM could potentially be revised in the future if their health stabilised: \*

*“Okay, I do need to take some anti-virals to try and get me through some of this. Eventually I came to terms with, well, I don't need to go on it for the rest of my life, hopefully...I'll be able to stop and have a break. I've been living with hope that the complementary therapies have managed to keep the whole thing at bay”*

This group had therefore revised the role of CM to form a part of their health maintenance routines alongside orthodox medicines.

The remaining fourteen participants did not have a history of using CM prior to becoming HIV positive. For these people a role for CMs in managing HIV health had in effect been created as a result of living with HIV chronically, by the ongoing and changing effects of ARV and HIV on their health. For this group use of CM was often associated with a change in the way they perceived health:

*“My idea of health prior to that was if there was something wrong I just went to the doctor and got it fixed up and that was it. It's like going and putting your car in for a service and putting some more fuel in. Now it's more looking at the whole thing in more depth”*

\*all quotations are taken from the participant interviews

## CONTROL OVER HEALTH

Many participants said that they felt that using CM had given them a sense of ownership over their health, as opposed to handing over control to the medical system. In contrast to ARV, CM practices were generally initiated by the individual based upon their personal motivations and decisions about how much to take or how often to take them. Participants also spoke of how their use of CM gave them the freedom to experiment with different CM modalities and practitioners. Using CM therefore introduced a degree of autonomy into health management, which was important given the perceived lack of control over medical dosing regimens:

*“I really hate this whole arsenal of pills, specially the anti-virals, I could miss the other ones...but the anti-virals have got this urgent thing about them...if you miss too many doses you're...risking getting viral resistance to that particular anti-viral...and that's another reason I want to go off them because I feel I'm being tyrannised by this routine”*

### CMs AS SAFE COMPARED WITH TOXIC DRUGS

There was an overall sentiment expressed by participants that CMs were relatively harmless substances and that they could experiment with using them without having to worry about side effects. Some participants also felt that CM would be able to repair the damage done by orthodox medicines. Despite believing that CMs were fairly benign substances compared with 'toxic' drugs, some participants also acknowledged that CM therapies could be harmful, such as high doses of vitamins, and that some herbs such as St John's Wort could interact with ARV. However, most participants felt that the potential for CM to be harmful was negligible compared to the extreme toxicity of ARV.

### INFORMATION SEEKING

The majority of participants continued to rely on medical doctors as the main source of information about ARV and about living with HIV. A general theme was that doctors and medical information were open to challenge, particularly in the context of the uncertainty of medical knowledge about HIV and discrepancies between how people were feeling and the results of their clinical markers.

*“But I do still rely on my doctors, I'll ask “what do they think I should do?” and I don't always necessarily go with what they say but I do like to know what they think and then I'll ask “Well, what do you base that on?”*

Most participants thought that it was important to obtain health information from a variety of sources. Several participants described researching information

about CMs from sources such as books, the internet, peers, pharmacists and doctors before making decisions about whether to use them. All participants except one said that the internet was an important source of information for them about biomedical treatments, CMs and lay experiences of using ARV and CM.

## CM PRACTITIONERS

When asked about guidance for using CMs only a few respondents, mostly those who had always used CM, saw CM practitioners regularly. Participants tended to research CMs over the internet, or to rely on word of mouth or doctors rather than visiting CM practitioners. A general theme was that CM practitioners complicated health management by recommending a broad range of therapies/remedies:

*"I did see a Naturopath...and he did a lot of different things with me for a while. But it gets to the point where you get "Well we should try this and we should try that" and "I'd like you to do a bit of selenium and a bit of zinc, and we need to get some calcium going here" and it's sort of whoa, where do you stop?"*

The majority of these participants had therefore made a decision to use CM in a largely pragmatic manner. The majority of participants had been living with HIV for almost 10 years. Due to having re-gained a fairly stable level of health they had either re-assumed old roles or were taking on new ones, such as employment or study. Most of the female participants had dependent children, and health management had to fit in with the parenting role. These data suggests that participants had to limit their uses of CM in order to have time to focus on other important aspects of their lives:

*"If you went into it in a serious way, it would be so all-consuming. I have too many other things to do. And so I think you have to pick the best of or what you think suits from both sides...and then you say, well I have made a decision, I'm not going to go all complementary, I'm not going to go all orthodox"*

## OUTCOME MEASURES/ CLINICAL MARKERS

When asked how they assessed the effectiveness of CM practices most participants spoke about considering the results of their clinical markers as well as more subjective measures, such as how they were feeling. However, the majority of participants felt that it was important to have scientific evidence for the efficacy of CM practices and many expressed disappointment at the lack of scientific research available. Most participants were more comfortable discussing CMs within a scientific framework, rather than within a holistic framework. However those who did believe in a philosophy of holistic healing

placed less emphasis on scientific evidence and trusted subjective measures, such as level of energy, to assess how these therapies were working.

*"I don't know whether what I noticed was psychological...and this is the problem with complementary medicine...unless there's actual studies and things like that, or published works, you don't know what you're dealing with really"*

## DISCUSSION/FURTHER RESEARCH

This research contributes to the knowledge around the meanings of CM practices to PLWHA in an Australian setting. These findings suggest that use of CM was strongly related to experiences of ill-health and of using pharmaceutical medicines, and changed as experiences and knowledge changed. The internet, publications, HIV doctors and peers were all important sources of information about HIV management and CMs. Amongst these participants, use of CMs was largely pragmatic and fitted into a scientific framework, rather than a more holistic framework. These participants placed importance on having scientific evidence to justify the use of CM. Rather than representing a rejection of the biomedical approach to HIV, CM use therefore reflected a general feeling that the biomedical approach was not enough to live a healthy life with HIV. These findings highlight a need for further research into the efficacy and safety of CM practices for PLWHA and also for discussion and dissemination of such information.

## FOR MORE INFORMATION

If you are interested in finding out more about this project, please contact Rachel Thorpe at the Australian Research Centre in Sex, Health and Society on:

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