Complementary Therapy Use in HIV/AIDS

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ABSTRACT

Objective: To examine the social psychological aspects of complementary therapy use in HIV/AIDS health care and to identify what happens in a person's illness management process when incorporated into their care for HIV-related symptoms.

Methods: Grounded theory research method guided sampling, data collection and analysis with 21 males at various AIDS service organizations.

Findings: A grounded theory model *Finding a Way to Live* was developed. Participants experienced a six-stage process whereby the HIV served as a precondition for a profound self-transformation; a commitment to and rediscovery of the meaning of life. Complementary therapies, referred to as 'tools' by the participants, were cited as an integral part of how people living with HIV found wellness within their illness. The type of therapy, meanings attached to them, intention for and frequency of use corresponded to where individuals were in the six-stage process. As participants began to experience personal growth, the nature of the therapies shifted from those being highly tangible and focusing on the physical self to those facilitating inner awareness, such as meditation.

Conclusions: The process of integration was a complex, ongoing process wherein complementary therapies were an integral part of facilitating learning, self-discovery and ultimately, healing.

Due to the unpredictable and chronic course, the severity of the symptoms and the debilitating side-effects of HIV/AIDS, as well as the limited efficacy of experimental treatments, those with HIV/AIDS work proactively to optimize their health during the illness. As a consequence, many with HIV/AIDS seek alternative modes of healing to supplement medical treatment and optimize or maintain health as long as possible.

The use of complementary therapies (CTs) is becoming increasingly widespread^{1,2} and includes such therapies as acupuncture, massage, meditation, yoga, homeopathy, herbal nutrition, and self-help groups.³ While the issue of efficacy of such therapies is stimulating research, such inquiry is beyond the scope of this article. Rather, we are interested in the process of seeking CTs, the reasons for integrating complementary therapy (CT) and the role that they play in the lives of those with HIV/AIDS, and the changing patterns of their use over the course of the disease.

METHOD

Grounded theory is used when little is known about the topic; the purpose of the research is to both explore and create mid-range theory; and the phenomena of interest is a process, changing over time.^{4,5} Grounded theory provides us with a lens into the phenomena from the perspective of the participants, yet at the same time enables us, through theoretical development, to obtain results that are applicable beyond the initial sample and useful to practice.

Setting and sample

The sample consisted of 21 gay, Caucasian males who had been experiencing symptoms of HIV infection and identified themselves as using CT for HIV-related concerns. The initial sample was obtained from various AIDS Service Organizations in a Canadian city with a population of 2 million and was purposefully solicited to meet the theoretical goal of the study. Participant characteristics included: age, 22-59 years; education, high school completion to some post-secondary or trade school preparation; average annual income, \$12,500-\$25,000. Most participants lived on some form of disability

La traduction du résumé se trouve à la fin de l'article.

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insurance or social assistance. Religious affiliations for 16 participants were varied. Time from diagnosis ranged from 2 months to 14 years, and, at the time of the interviews, participants reported being at various stages of the disease, many experiencing HIV-related symptoms.

Permissions were obtained from University ethics committees and from the recruitment sites. Informed consent was obtained from each participant prior to commencement of the interview.

Data collection

Participants were interviewed individually in counseling rooms at various agencies throughout the period May to October 2000. Measures were taken to ensure confidentiality and anonymity. Interviews were 1-2 hours in length and commenced with a broad, open-ended question, inviting participants to describe in their own words what they did, aside from taking prescription medication, to make themselves “feel better.” As data collection progressed and theoretical explanation of emerging categories became apparent, participants were asked increasingly specific questions. Follow-up interviews focused on verifying information and conjectures about the emerging theoretical scheme, and participants were sought whose experience could refine and expand the limits of the emerging conceptualization.

Data analysis

Interviews were first transcribed and checked for accuracy. Data were then sorted into categories according to content using Microsoft Word® and multiple windows, maintaining links to the original interviews, participants and the text location in the original transcript.⁶ As data collection proceeded and categories began to saturate, sampling strategies changed. Participants were purposely sought out either because they represented negative cases or to provide data in areas that were thin in the data set, thereby achieving variation in data. We ascertained rigor by processes of verification. Once data were dense enough to be synthesized, the basic social process⁷ was identified, and stages in the process were located and outlined. Linkages, causes, and consequences of each stage were then described and the resulting mid-range theory was verified with participants. Finally, we returned

to the literature to ascertain commonalities, and these commonalities served as a further indice of rigor and generalization.

RESULTS

The search for CT began when participants first suspected they were HIV positive, around the time of diagnosis, or when they first began developing symptoms. These therapies took various forms, changed over the course of the disease, and became an integral part of the participants' lives. These therapies were referred to by participants as ‘tools’ for healing, and their use was referred to as ‘work’, indicating the effort required to locate and adhere to their utilization. Through the use of these therapies, the participants “found a way to live” and considered themselves “the makers of their own healing” (see Figure 1). This

healing was not the healing of the physical body, but rather a mental and physical state achieved following a phase of serious grieving and acute symptoms that threatened life. *Finding a way to live* is a transcendental revaluing of one's spiritual and psychological states in which one comes to disregard, not only one's bodily ailments, but one's body per se. This shift is attained by changing one's attitudes, one's values, and one's approach to life itself.

While the three phases in this model – searching for tools to sustain wellbeing, searching for tools to go inside and searching for tools to secure wellbeing – occur somewhat sequentially, this is not a linear model.

Tools for sustaining wellbeing

The search for *tools for sustaining wellbeing* is the first phase in *Finding a way to live*. *Finding out* is shaped by the uncertainty

Figure 1. The process of *Finding a Way to Live*

TABLE I

Tools Utilized Along the HIV/AIDS Illness Trajectory

Tools for Sustaining Wellbeing	Tools for Going Inside	Tools for Securing Wellbeing
1. Using herbs & supplements (garlic, milk thistle, essential fatty acids, spirulina, DHEA)	1. Meditation	1. Being self aware
2. Using various types of massage	2. Praying	2. Living in the moment
3. Exercising (resistance training)	3. Journaling	3. Finding a balance
4. Paying attention to diet	4. Accepting	4. Listening to one's intuitive voice
5. Practicing yoga	5. Forgiving	5. Sharing with others one's experience of living with HIV/AIDS
6. Quitting work		
7. Keeping busy		
8. Seeking the advice of others		

Tools for sustaining and going inside are continued throughout the process

surrounding the progression of the disease and the person's emotional response to diagnosis. Knowing that a cure for HIV was not available and having to manage their illness for an unknown period of time caused great distress:

I got very caught up in, in the emotional part of it. In other words, the body may not be so bad but the mind can take you on these horrific journeys to hell – you know, obsessing about what could happen, or how long have you got or who gave it to you or you know, all of those things that can contribute to your poor health through stress.

Preparing for the onset of health concerns characteristic of HIV/AIDS, participants sought tools to assist in sustaining their wellbeing (see Table I). These tools included using herbs and supplements, massage therapy, exercising, doing yoga, quitting work and keeping busy.

They make me the healthiest person I can be and are there to prepare me for any sort of disaster that might happen whether it is losing my partner or getting full-blown AIDS. The name of the game is to stay as well as possible for as long as possible so that I can keep on with my normal life.

Participants constantly sought advice from other HIV positive men. Importantly, the use of these “tools for sustaining wellbeing” in various forms continued throughout their illness.

Tools for “going inside”

Taking a Turn for the Worse: Once their health deteriorated and opportunistic

infections appeared, participants felt life was meaningless and prepared to die. Many lost hope and felt that they were unable to do anything more for their health. They said as they went “downhill”, that they were “giving up on life”; they became isolated, exhausted and disconnected from others:

I took about 95-100 pills per day plus various fluids, you know, sleeping medications, anxiety medications. My whole life was you know, number one trying to be pain free, number two trying to stay alive. That wasn't even really that important. It was all about—ok, I have to see this physician tomorrow, this specialist tomorrow, have this test tomorrow. You know, did I have any real purpose left?

This rapid physical deterioration resulted in the retreat ‘into their minds’ to escape bodily breakdown. They felt their bodies were no longer ‘safe,’ they were exhausted, and all of their energies had been spent toward resisting and concealing HIV.

Going Inside: Participants perceived this turn for the worse as an indication of their life falling apart. They reported that their ‘fighting spirit’ left, and felt their only option was to commit to life or commit to death. This disconnection and disassociation from everyday life involved focusing more on one's emotional and spiritual dimensions:

I started becoming hugely aware of spirit because I felt that I was becoming more of a spiritual being than a physical being. My

body failed and I felt that my spirit was growing...I didn't have the energy to do anything but think and pray and meditate. My body had stopped and my spirit carried on.

An important transition in committing to life was accepting the fact they actually had HIV. Their identities were changed to incorporate the virus and the disease, and the anger, fear, guilt, and shame. To achieve this connectedness with oneself, to pass through the anxiety and fear, they sought self-reflection and solitude:

It is about looking past the HIV a little bit more. I had to go, ‘Okay, this is not what I thought.’ I guess some things happened along the way that got me to this place. I needed to accept that and move on or else it was going to be all over. I had to accept myself and let go of this baggage and guilt I had been carrying around for a good part of my life, you know?

The tools for going inside included meditating, praying, journaling, accepting and forgiving. These enabled a self-transcendence, resulting in a self-acceptance, a forgiving of self and others, and deciding to ‘drop the past’ and live in the present. They experienced emotional release with resistance melting away and this emotional catharsis created an opening for healing:

I felt really open. I felt like I started to let go of all of the closedness of living in my physical world and started opening up my spiritual being and letting in spirit. It had changed me. I had shifted. I was reborn in a way. I became totally nonjudgmental of people, became much more loving, much more accepting because I was becoming someone else.

This resulted in renewed energy to resume daily activities. Some participants even began to make plans, such as returning to school or starting their own business.

Tools for securing wellbeing

The shift from illness to wellness had profound implications. While the participants continued to use illness benchmarks, speaking of viral loads and declining CD4+ counts and symptoms, they did not dwell on their bodies. While they remained uncertain and apprehensive about trusting their bodies, they spoke of wellness in terms of balance and overall wellbeing. While transcending the experience, they expressed a newfound confidence and trust

in life where HIV was no longer in the forefront and, for many, faded into the background:

It has become a way of life for me. But in a container, in the background...It is not going all over the place, I have got control over it. So, the word I am looking for is manageable. It is in the category of a manageable illness, as in I could live to be 70 or 80 and manage this no problem.

By this time, participants had gained self-awareness and knowledge about which tools were helpful for them *thereby securing wellbeing*. They used a core set of tools – ‘positive habits’ – listed in the third column of Table I. These were primarily ways of living, an attitude towards life. However, while they were considered by the participants as CTs, such things as acquiring self-awareness, living moment-to-moment, obtaining a balance, listening to one’s intuitive voice and sharing one’s experience are not considered CTs in the literature. These tools were not intended to alleviate symptoms but more to contribute to an overall sense of wellbeing and to strengthen the body’s natural capacity to fight disease. At this stage, therapies considered to be helpful from earlier stages, intended to target physical symptoms, including using herbs, massaging, praying and meditating, were also used as needed.

Awareness and balance became central components of participants’ new ways of living. Their lives were simplified, activities that might lead to an imbalance eliminated. Balance was the conscious act of dealing with complex demands and putting aside unacceptable impulses that put them off kilter:

I no longer try to do a million things in a day. I get lots of rest. I try to eliminate unnecessary stress from my life. This is really important to my sense of balance and I just try to be as involved in life as I possibly can be in a way that suits me and have eliminated ways that don’t suit me.

All participants spoke of helping others with chronic conditions, of initiating support groups, providing workshops and acting as resources for those living with HIV/AIDS. They reported a heightened awareness and sensitivity to the needs of others and an urge to share:

A very big part of my healing strategy is to be proactive in the process...They are taking their disease and they are doing something

that is going to hopefully benefit everybody including themselves. And they will live longer and healthier lives because of it – and more fulfilling lives.

DISCUSSION

Understanding the role of CT in attaining health in the face of illness provides a new perspective on functions of CTs. This perspective is holistic and congruent with the underpinnings of health promotion. Furthermore, this shift from focusing and facing illness, one’s symptoms, loss of body functions and changes to the focus on health and “backgrounding” illness has been noted by Paterson,⁷ and others,^{8,9} and is an important strategy to optimize health in many chronic illnesses.

The model of *Finding a Way to Live* has many components that may be verified in other research, extending the findings beyond the context of this project. These commonalities, albeit confirming various components of the model, enable and increase the generalizability of the findings. For instance, extreme awareness of death immediately following HIV diagnosis and the resulting anger has been noted by McCain and Gramling,¹⁰ and developing the modes of coping has been documented by Reeves¹¹ and others.^{12,13} Ramsum¹⁴ and Gloersen documented the importance of achieving a sense of wellbeing (including forgiveness) among persons living with HIV.

In other chronic illnesses, Jensen and Allen¹⁵ suggested that finding a balance requires regaining and sustaining a degree of control over one’s life and illness, the outcome of which is a sense of harmony and fulfillment. Beck¹⁶ extended this notion to a sense of balance between the ill person, others and their environment.

From a broad perspective, HIV/AIDS is a disease with an uncertain course, unstable and voracious symptoms, experimental treatment with multiple side effects, and a poor prognosis. The model *Finding a Way to Live* may be also applicable to other chronic diseases with these same characteristics, such as some forms of cancer.

As this model was developed by interviewing participants who used CTs, we do not know the course of illness of those who do not use CT. While further research would answer this question, it is possible that the broad definition of CT would

make it difficult to identify anyone with HIV/AIDS who did not use CT. Further longitudinal research is also needed to determine the use of these therapies as HIV/AIDS participants approach death.

In summary, we have identified a model that depicts the integral relationship CTs have in the health-seeking behaviour of people with HIV/AIDS. The definition of CTs derived from participants was exceedingly broad, but fascinating when considering that such health-seeking behaviours had therapeutic benefits.

Finally, it is worth considering the implications of the research for the health care system. Driven by increasing cost constraints, an aging population, and consumers’ desire to take greater charge of their own health, strategists are calling for greater emphasis on disease prevention and health promotion, self-care, and integrated care. Both the CAM research agenda¹⁷ and our findings dovetail with these trends, creating opportunities to link health reform with the desires of our participants for a health care system that supports and enables their work in finding a way to live. This raises a new set of questions. Are we doing the right things in our health care system for HIV/AIDS (and other chronic diseases)? How might we coordinate health care services better? Are we measuring “health” and “health care” in ways that are valid, progressive, and useful for improving user satisfaction, quality of life, and health reform? Our work raises as many questions as it answers, and that’s how it should be. Our hope is that the questions stimulate further research, to craft a research agenda that aligns with the experiences of the user even when those are very different than what we initially expect.

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RÉSUMÉ

Objectif : Étudier les aspects psychosociologiques du recours aux thérapies complémentaires dans le traitement du VIH/sida et définir les étapes du processus de prise en charge individuelle de la maladie lorsque ces thérapies sont intégrées dans le traitement des symptômes du VIH.

Méthode : Une méthode de recherche à base empirique a guidé l'échantillonnage, la collecte et l'analyse des données de 21 clients masculins de divers organismes de services aux sidéens.

Constatations : Nous avons élaboré un modèle théorique à base empirique (« Finding a Way to Live », ou « trouver moyen de vivre »). Les participants sont passés par six étapes où le VIH devait déclencher une autotransformation en profondeur, un engagement envers la vie et une redécouverte du sens de la vie. Selon les participants, les thérapies complémentaires, appelées « outils », font partie intégrante d'une recherche du mieux-être pour les personnes vivant avec le VIH. Le genre de thérapie, le sens qu'on y rattachait, l'intention visée et la fréquence d'utilisation variaient d'une étape à l'autre. À mesure que les participants commençaient à vivre une croissance personnelle, la nature des thérapies évoluait, passant des traitements physiques tangibles aux traitements favorisant la conscience de soi, comme la méditation.

Conclusions : L'intégration s'est faite selon un processus complexe et continu où les thérapies complémentaires ont joué un rôle clé vers l'apprentissage, la découverte de soi et, en bout de ligne, la guérison.

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Hearing: When your newborn does not respond to noise at three months... look towards a speaker or sound at three to six months... smile when spoken to at three to six months or vocalize and bubble alone or with others at three to six months. When your 18 month old does not point and gesture to call attention to objects or events... does not use words to get what he wants or continuously pulls at ears. When your three year old turns up the television or radio louder than other family members or does not hear you call from another room.

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