HIV, Stigma and Discrimination: What Can Shiatsu Offer?

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Shiatsu has a unique contribution to make in managing HIV for a range of clients. Many people who are HIV positive suffer from isolation and lack of physical touch. Shiatsu can provide a way of nourishing this need, whilst also strengthening self-acceptance.

I have been working for 2 years as a volunteer Shiatsu practitioner within the Bristol branch of the Terence Higgins Trust (THT), a national charity, which focuses on HIV. All the clients I see on my weekly visits to THT are HIV+. There is a strong emphasis on confidentiality: “We are here to listen, not to talk” as the strapline puts it. This emphasis on confidentiality is of crucial importance in the case of HIV, due to the stigma the disease carries, and it allows the building of a supportive community for people with HIV.

I come from South Africa originally and I have friends there who have worked hard on changing health policy at the national and provincial levels to address the vast scale of the problem. One of my family members has also been working on a daily basis as a GP with many HIV+ patients. So when, as a newly qualified Shiatsu practitioner, I heard of this opening to volunteer I felt excited to join in. I also felt quite anxious, being someone who knew probably only an average amount (i.e. not much at all) about HIV - its transmission, the drugs, the side effects and so on.

The initial training weekend I received at THT covered transmission routes, safer sex, HIV testing and viral loads. Training with a new group always takes some emotional effort and I found this initial training quite heavy going with the awareness of mortality and the suffering we were confronting. However we also heard HIV+ people sharing their experiences of being positive, which was inspiring.

Stigma and discrimination

HIV+ is often described as bringing with it a cycle of stigma and discrimination (Aggleton et al. 2005). ‘Stigma’ comes from Classical Greek and means a marking on the body to indicate difference and social exclusion (for example indicating a slave). In a modern context, stigma is being marked symbolically as different, separate, and having a ‘spoiled identity’, without social position or recognition (Goffman, 1963). Although in the case of being HIV+ the stigma is invisible, it still carries considerable force.

Some people who are HIV+ may have considerable physical and emotional side effects from the drug treatment, although others do not. Some feel the stigma acutely and internalise it, feeling that they carry the burden of shame around with them all the time. Others may see it more in terms of having to navigate around prejudice, or learning to live their lives on their own terms.

Getting a diagnosis of being HIV+ can bring strong emotional reactions of fear, disorientation and hopelessness. However it can also provide the impetus for change and for making choices to live in a new and positive way, providing the stimulus to sort out issues that have impeded the person’s life progress e.g. acting out addictive behaviours.

The impact of the stigma associated with HIV is likely to be particularly strong when developing a new relationship. First there is the difficulty of meeting a suitable partner and negotiating safe sex, but then comes the real quandary of when to reveal ones positive status. If you come out too soon
as HIV+ the budding relationship may be lost before it has started - waiting too long may be seen as a betrayal or shock to the potential partner. Thus the stigma associated with HIV can cause relationship problems and breakups.

Taking a wider view, HIV has been associated with high-risk groups such as intravenous drug users and sex workers who were already stigmatised. It has also tended to feed into wider forms of discrimination - such as homophobia, racism and sexism - all of which tend to ‘blame’ victims of the illness. Infection, stigma and discrimination have often formed a mutually reinforcing cycle (Aggleton et al. 2005).

However the view that HIV is a death sentence is no longer accurate - particularly in an affluent country with a well-developed health service like the UK. A large scale review of research (May et al. 2011) showed that life expectancy for people, who are HIV+, has improved to the point where aging with HIV will become a common phenomenon. Early diagnosis and treatment remains important as treatment is much more effective when there is still a high count of CD4 (specific antibodies attacked by the virus) in the blood stream (Carter 2011).

The improvements in the available HIV drugs since the 1980s are dramatic in terms of survival and longevity, but also equally impressive in improving quality of life. As one client put it to me:

“Twenty years ago I would be dead, 10 years ago I would have terrible symptoms, now I just take a small pill in the morning”.

Of course there is variation between individual experiences - another client felt that there was no perfect HIV drug for him so it would always be about balancing which medication has the least unpleasant side effects.

Tiredness, and in Shiatsu terms, depleted Kidney energy, is common among the clients that I see. A Shiatsu colleague said to me that he found a lot of Triple Heater when he worked in the THT and I have found that a useful idea to explore, particularly in relation to one client. I am often drawn to Heart and Heart Protector I think because of the emotional resonance and also drawn to Kidney due, I think, to the toll of processing the powerful medication. In terms of western medicine kidney and heart disease are growing problems as the HIV+ population ages (Terence Higgins Trust website). In terms of eastern diagnosis I feel that the Kidney Ki Deficiency powerfully reflects how the fear of death and the struggle of the clients’ lives drains their core energy.

Living with HIV creates a highly medicalised identity. Once you have been diagnosed, monitoring your health is a central part of defining who you are and the life you lead. You’re required to attend hospitals for frequent check ups and blood tests and there can be frustration with GPs who are not necessarily up to speed with how other health conditions or crises can interact with HIV and its treatment.

What then is the place for Shiatsu in this context? I see my role very much as providing a complementary therapy, working alongside the drugs and the monitoring conducted by medical personnel. Indeed ‘being alongside’ is probably the best metaphor for the Shiatsu practitioner’s role in relation to HIV+ clients.

A big issue in many clients’ lives is that physical touch from other people is often missing altogether or restricted to rather intermittent contacts. Shiatsu, as a form of physical and emotional contact, feels nurturing and builds trust and so provides an opportunity for people living with HIV to fill a gap.
in their lives. Through Shiatsu, clients receive acknowledgement for the struggle with their health problems and space to let go (at least temporarily) of the stigma and discrimination that can be involved with HIV. Of course, as with all clients, each individual brings with them their own particular issues.

As clients talk, they tend to split their problems into physical and medical problems on the one hand and emotional issues on the other. They have little sense that Shiatsu practitioners may weave these together via theories of energy flow through meridians, or Kyo and Jitsu areas etc. Often a client will discuss e.g. visiting a doctor for lower back pain, and then be surprised that it goes after a Shiatsu treatment!

A related division lies between the perception of counselling (as a painful, challenging experience) and Shiatsu (as calming, pleasing and nurturing). So one client told me: “I like to go to [the counselor] first to make me cry, and then come to you to make me feel happy again.”

However some clients do want to talk, sometimes at length and in some cases hoping for a less challenging listener than the counsellor. Others choose Shiatsu over counseling in order to keep more control of what they explore and what they don’t or some just want to lie down and relax and let someone else to be ‘on guard’ for them. However the physical and emotional contact of Shiatsu leads most clients to want to talk about their problems to this ‘massage person’.

The concerns clients raise often go back to revisiting difficult relations with their parents and/or difficult childhood experiences, which have affected their whole adult life and led to ‘acting out’ of one form or another. This acting out can include what may be seen as addiction, to blank out the emotional pain, as isolation locks you into an unhelpful focus on illness and unhappiness.

Working with someone who has an incurable disease can be an emotional process. With one client I had a sudden moment in the middle of a treatment when I was overcome by a sense of his mortality. The thought “I could lose him” flashed before me. On another occasion a client said “Thank you for loving me the way my mother couldn’t”. Shiatsu provides an important shift, making a client feel accepted and acknowledged, they are able to relax and to be accompanied for a small part of their journey.

**A Footnote on Support**

I feel appreciated by the staff at THT as I offer something they simply can’t - in a counselling setting touching clients is a taboo. There is a strong feeling of a supportive community at the Terence Higgins Trust, between all the service users, volunteers and staff. Shiatsu and its physical contact is very special for the clients and for most of the time I have been the only Shiatsu practitioner volunteering in the Centre (I doubled my hours when an existing practitioner left). There are other massage therapists and Acupuncturists though I have barely met any of them as we use the same therapy room but at different times. Whilst the staff are very supportive, supervision in the professional sense is supposed to be taken outside - in my case through the Bristol School of Shiatsu. This really helps with hearing difficult things and not always feeling able to work them through on my own.

**References**


A contribution to a recent exhibition at Terence Higgins Trust Bristol

2016 – me now …
‘Contracting HIV has been the most positive experience of my life (in more ways than one)
It’s not a death sentence! I am happier than I have ever been
I am healthier than I have ever been.
It’s my secret to tell if I want to
It doesn’t belong to anyone else to tell
I value my life and family more than I thought was possible
I am a fantastic mother and grandmother
LIFE IS GOOD’.

From Terence Higgins Trust, Bristol, World AIDS Day Exhibition, December 2016