

行政院國家科學委員會專題研究計畫 成果報告

主流與另類的整合：慢性傳染病、癌症與過敏疾病患者的免疫觀與行為(2/2)

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Introduction

Alongside the development of immunology in biomedical sciences in the mid twentieth century, immunity has become an emergent health concept among laypersons (Martin, 1994). Yet this emerging trend exists not only in Western societies such as US, the concept of immunity also increasingly being aware and applied in the non-Western society like Taiwan (Lew-Ting, 2000).

The concept of immunity is particularly easy to be comprehended in the context of infection or infectious diseases (Martin, 1994), and perhaps even more so in the case of acquired immuno-deficiency syndromes (AIDS) in which the term immunity is inset as part of the disease name.

Then, what would immunity be conceptualized and the state of one's immunity be captured in the circumstance of HIV infection? And in face with a disease, immunity is certainly to be linked to the development of disease course and the effectiveness of treatment. In the case of HIV/AIDS, since the highly active antiretroviral treatment (HAART) has widely used, particularly in some developed countries, an unexpected challenge and a trade-off that with the effect of chemotherapy and therefore the life quality of the HIV infected increase, the unprotected sexual contacts and therefore the prevalence of HIV seropositives rapidly escalates. This phenomena, which is currently referred as "HAART optimism," has been intensively explored recently (Van de Ven et al., 1999; Miller et al., 2000; Ostrow et al., 2002; Venable et al., 2003; Elford, 2004; Laboy-Muñoz et al., 2005), and the findings are controversial. The preliminary conclusion, however, is tentatively reached by a meta-analysis carried out by Crepaz and colleagues. Their analyses indicated that HAART *per se* and a desirable outcome such as undetectable viral load did not encourage risky sexual behavior; it is people's beliefs about HAART and viral load that is likely to promote unprotected sex (Crepaz et al., 2004).

In this article, the concept of immunity is to be explored in the context of HIV/AIDS among a group of HIV infected laypersons. Among some of them the idea of immunity or immune function has never been existed before the diagnosis of HIV seropositive. In addition to illustrate their conceptualisation of immunity and the meanings they attached to HIV infection and HAART, their strategies for coping with the disease and its impact on daily living are to be explored.

Method

This research applied both qualitative and quantitative methods to explore how HIV-positive persons construct the concept of immunity and the way they deal with

immunity related reality. Based on four premier in-depth interviews, a semi-structured questionnaire was developed and used to collect data through face-to-face interviews. Participants were recruited, on the basis of convenience sampling procedures, from clinical settings, non-governmental organizations, half-way institutions, and snowball connections. A total of 103 HIV-positive persons were interviewed during the period between October 2003 and April 2004.

The participants

As shown in Table 1, the sample was predominately male (92.2%), and among them, 61% were man who has sex with men (MSM), while all female are heterosexual. The mean age of respondents was 40.3 years old, with 81.6% older than 30. Although the majority (90%) were still in workforce age, and many received high school or above education, only half (52.4%) had regular jobs. As to their HIV medical history, while most (67%) had been diagnosed less than 5 years, their “HIV-positive career” ranged from one month to 20 years. The self-reported CD4 count ranged from a minimum of 9 to as many as 1500, with a mean of 372. Twenty-nine (28.2%) had the count less or equal to 200, and 64 (62.1%) less than 500, which indicated CD4 depletion generally existed in the sample. The range of viral load was certainly greater (0 to 780000), and 50 persons claimed a zero viral-load count.

The interviews

To take the participants’ convenience and privacy into account, interviews mainly took place at clinics, the researcher’s office, or community-based support institutions. Before proceeding with the interviews, the members of our research team explained the purposes of the study and assured confidentiality. Only when informed consents from the participants were obtained did the interviews start. Each interview lasted a minimum of 20 minutes to a maximum of 145 minutes, with an average of 53 minutes. With participants’ approval, 97 interviews were tape recorded and transcribed by the members of the research team. Participants were reimbursed NT\$500 (about US\$15) after the interview.

The conversations were usually initiated by asking the participants to provide their ideas about and understanding of CD4 (the term was expressed in English), and then followed by asking specific questions related to this concept and a specific concept that would commonly be raised and articulated in the midst of narratives – immunity. Key questions included: (1) Would you say to maintain good immunity in your daily life is very easy, easy, fairly easy, difficult, or very difficult? (2) How helpful would you say the Cocktail Therapy is to enhance your immunity? Would you say it is very helpful, helpful, fairly helpful, unhelpful, or very unhelpful? (3) As a HIV-positive person is concerned, would you consider having sexual activities might

lower one's immunity? It might do, might not do, or depends. For each question, all participants were further probed to elaborate their answer and provided colloquial responses.

Table 1. Sociodemographic and medical characteristics

Characteristics	Frequency (n=103)	Percent (%)
Sex		
Male	95	92.2
Female	8	7.8
Age		
0-20	2	1.9
21-30	17	16.5
31-40	43	41.7
41-50	25	24.3
51-60	10	9.7
61 above	6	5.8
Education		
Primary and below	10	9.7
Secondary	18	17.5
High	40	38.8
College and above	35	34.0
Employment status		
Full time	41	39.8
Part time	13	12.6
Unstable employed	12	11.7
Unemployed	37	35.9
Sexual Partner		
Male		
Always male	58	61.1
Always female	14	14.7
Both sexes	20	21.1
Refuse to answer	3	3.2
Female		
Always male	8	100.0
Time since diagnosis (year)		
Less than 1	23	22.3
1-5	46	44.7
5-10	20	19.4
10-15	11	10.7
15 above	3	2.9
CD4 count		
≤200	20	19.4
201-499	44	42.7
≥500	30	29.1
Unknown	9	8.7
Viral load		
≤200	54	52.4
201-5,000	8	7.8
5,001-10,000	5	4.9
10,001-100,000	13	12.6
>100,000	6	5.8
Unknown	17	16.5

Results

Immunity as reflected from CD4

In answering the question “What do you think about CD4?” these participants provided diversified responses; some were neutral, objective statements, and some were personalized accounts. Overall, a knowledgeable cognitive profile revealed. These HIV seropositives were truly lay experts in CD4.

Conceptualization of CD4

Less than one fourth of the participants (n=23) did not specify what CD4 exactly represents or denotes. Most of them were told every time by their physicians their CD4 counts (accompanying with viral load) but they have never tried to figure out what CD4 means. Yet obviously they all knew that higher reading of CD4 count is better and desirable.

Of the remaining 90 participants, 11 did not relate CD4 to immunity but indicated that CD4 was a type of indication or that CD4 counts reflected viral load. The accounts of the other 79 participants, however, were all immunity relevant, mirroring a strong concern over immunity and its impacts. Statements such as “CD4 itself is immunity or CD4 is equal to immunity” or “CD4 is partial immunity; a part of overall immunity” recurred in their narratives. In the context of immunity, CD4 was frequently referred to white blood cells, antibody, and macrophage, etc. If “partial” or “part of “ was stressed, the other traditional conception of health status “personal constitution” was sometimes added. As a result, CD4 has a function to fight with virus, bacteria, or other enemy, as the majority of the participants asserted.

Immunity concerns and obsession

Whereas these HIV seropositives held a basic understanding of CD4, some of them seemed greatly preoccupied with their own CD4 status and its relevance to health condition. Others, however, simply made general commentary, trying to disclose their beliefs of this clinical indicator. Around three types of response were observed.

These respondents held relatively advanced knowledge about CD4 and AIDS. Each of them expressed distinctive thought about CD4 and their own health status.

Obsession

Obsession was characterised by being preoccupied with CD4 count enormously, to which the HIV suffers referred virtually any perceived changes in bodily state and physical conditions. Anxiety was thus generated from unremitting attentiveness to the up-and-down of CD4 count.

Indifference

In contrast to obsession type, participants of indifference type expressed plainly

their inattentiveness to CD4 count. Three categories of responses can be observed. The first type of response paid much more attention to the side-effect of treatment rather than their CD4 counts. After all, as they asserted, it was the side-effect that caused unbearable suffering. The second type of respondents emphasised what they have observed and felt empirically from their own bodily experiences. The CD4 counts seemed unlikely to determine one's overall physical health and overall well-being. Their own subjective assessment is more valid.

Neutrality

The neutral stance was characterized by granting the importance of CD4 but at the same time being able to be emancipated from its influence psychologically. Neutral persons were unwilling to use the CD4 count as the only indication of well-being. They just learned to live with HIV/AIDS and, specifically, their CD4 and viral load status. To them, the most impressive evidence supportive for being detached (but not being indifferent) from those clinical indicators came from daily observations of certain out-of-expectation examples. That is, there were healthy and capable persons who have CD4 count less than 10, and fragile and ill persons who had CD4 counts more than 500. They were patients who coped with their illness with evidence-based observations.

Immunity maintenance in daily living

In response to the question: “Would you say to maintain good immunity in your daily life is very easy, easy, fairly easy, difficult, or very difficult?” more than half (64.1%) considered it very easy or easy, and about one-fourth (25.2%) felt difficult or very difficult (Table 3).

Table 2 Easiness to maintain immunity in daily life

	Frequency (n=103)	Percent (%)
Very easy	3	2.9
Easy	63	61.2
Fairly easy	9	8.7
Difficult	23	22.3
Very difficult	3	2.9
Unknown	2	1.5

For persons who considered immunity maintenance easy and painless, “taking medicine regularly” was the top tenet. Beyond that, healthy life style and regular rhythm of daily living were emphasized enormously. Many respondents confessed that they were used to live a life of debauchery and disorder. The new role of HIV seropositive prompted them to make a radical change of their patterns of life. Not only the physical aspects of living, such as sleep, diet and physical activities, were practised, mental wellness was also very much concerned about. This comes from their firm beliefs in the psychosocial mechanism of immunity and immune functions.

However, to others immunity maintenance was always demanding and painstaking. Two hurdles confronted those HIV afflicted victims to maintain or improve their immunity status. First of all is their meagre living condition, which enmeshed them into a struggle for a minimum mode of survival. The thought of “immunity,” instead of merely surviving, or even enhancement of immunity is nothing but a luxury. The other frustration came from their health status. Whether judged or felt by clinical indicators or subjective perceptions of health status, poor health status dispirited a desire for betterment.

As to persons in between the extremity, their typical responses were nothing serious or not-a-big-deal. They would just like to live a normal and usual ways of life. The perceived effect of cocktail therapy (HAART)

Over 70% of the respondents think cocktail therapy is helpful to enhance one’s immunity. Indications by which people judge the effectiveness of the therapy include subjective feeling, objective observation of physical changes, and most commonly addressed – the readings of clinical indicators. The commonest evidence for positive therapeutic outcomes is the rise or stability in CD4 counts, or the decrease in viral load. In this perspective, these numerical lab data, instead of their personal perceptions, represent the status of their immunity. This also explains why some respondents still recognize the effect of the therapy even if they feel quite sick. It all depends on which criterion one uses to assess his status of immunity.

Table 3 Helpfulness of Cocktail Therapy for immunity enhancement

	Frequency (n=103)	Percent (%)
Very helpful	9	8.7
Helpful	65	63.1
Fairly helpful	7	6.8
Unhelpful	11	10.7
Very unhelpful	1	1.0
Never take the medication	10	9.7

The surfacing of side effects accompanied by Cocktail therapy usually resulted in condemning the therapy as helpful. On the other hand, some respondents may comment positively on the therapy since they have felt much better by alleviating their sufferings caused by AIDS related syndromes, such as fatigue, losing appetite, or insomnia. However, for other respondents, the therapy might be considered unhelpful because, they believed, the therapy actually functions as virus-killer, which is irrelevant to immunity enhancement. Thus, with this idea in mind, they developed other strategies, rather than adherence to the therapy, to help boost or maintain one’s immunity.

Although some respondents undervalued the effect of cocktail therapy on

immunity, they still recognized its helpfulness, due mainly to its obvious effect on CD4 count. The following is their theory: after the virus being killed or suppressed by the therapy, the CD4 counts will be able to rise. A number of respondents who embraced this “microbiological” perspective called this mechanism as “positive side effects.”

Other strategies

Regardless of their overall assessment of cocktail therapy, the majority of respondents developed other strategies to maintain or enhance their immunity. Everyone had his own prescription for immunity maintenance and enhancement. Basically, six domains of strategies were drawn from their narratives: changing health practices, regular exercise, modifying risk behaviors, dietary modification, using complementary and alternative medicine, and maintaining mental health. The most commonly adopted were changing health practices (93.2%), maintaining mental health (87.4%), and dietary modification (85.4%).

Apart from practices like healthy sleep and being aware of the body’s change, there were 39 (37.9%) respondents indicated decreasing sexual activities as one of their strategies. It is also intriguing that when it came to maintaining or enhancing immunity, as many as 72.8% of respondents considered keeping peaceful mood as an important strategy, implying a commonplace body-mind unity inherent in their conceptualization of immunity.

Food and diet was also deemed critical. With regard to ordinary diets increasing consumptions of beneficial food items such as vegetables and fruits were emphasized. On the other hand, risk categories like uncooked foods, or the undesirable such as spicy foods or too much meat were avoided. Food supplements such as vitamins and minerals, bee propolis, or Chinese style tonics like ginseng, swallow’s nest soup, chicken essence, cordyceps, and five elements vegetable soup were also commonly mentioned. In addition to what to eat, some respondents also address on principles regarding *how* to eat, for example, keeping balance in diversified nutrients and eating regular amount at regular time.

More than one fifth (21.4%) of respondents used alternative and complementary medicine. Taking prescribed Chinese medicine was the most often mentioned, and massages the second. The rest of modalities applied included acupuncture, Chi-gong, and meditation. There were 9 respondents joined research projects, mostly randomized control trials, to be the subjects using items such as *flower essential* or *energized water*.

Obviously, it was commonplace for our respondents to use various strategies to maintain and boost their immune function. However, some respondents also pointed out that the purpose of their strategies were not limited to immunity enhancement

alone; to relieve side effects associated with conventional cocktail treatment, and to achieve relaxation and stress reduction were also important. And, fortunately, none of our respondents reported replacing conventional treatment by those self-engaged strategies. Thus, we can conclude that these practices were mainly used as complementary rather than alternative strategies.

Sexual behavior in relation to immunity

Being HIV infected, there were only 14 persons (13.6%) considered sexual behaviors deteriorate their immunity (Table 4). Respondents who disagreed the above statement (32 persons, 31.1%) held a theory that sexual behavior has nothing to do with immunity; it is a way of discharging one’s emotionality and wearing out the energy and it poses no harm to immunity even one does it frequently. Around half (47.6%), however, gave an indecisive response – it depends. Their narratives revealed two concerns. The first is about safety. They would be willing to engage in sex only when safer sex was assured and practiced. The second is about the health. Only while sex was done in a right way and with an appropriate amount (frequency) does it pose no harm and is even beneficial to immunity.

Table 4 Immunity deterioration due to sexual behavior in the case of HIV positive

Category	Frequency (n=103)	Percent (%)
Yes	14	13.6
No	32	31.1
It depends.	49	47.6
Don’t know.	8	7.8

Discussion and conclusion

Based on the major findings of the study, the immunity has been used in a variety of context, not simply restricted to clinical arena. The most importantly, we are not confident pointing out that the crisis of so-called “HAART optimism” (Van de Ven, 1999; Pickett, 2003) was not commonly seen among our respondents. If this is the case, apart from their adherence to regimens and their quality of life, a stress on safer sex should be one of the foci of current HIV/AIDS prevention and control in Taiwan, such as the case management programs that have been launched in Taiwan. Accordingly, the following four aspects of services-oriented suggestions are proposed:

1. The impact of mental/spiritual factors on the immune system

Most HIV infected persons, at least in our study, held body-mind integrated concept of immunity, they greatly emphasized the significance of mental health and interpersonal relationship, or even CAM use in their response to disease. The health professionals in clinical settings who provide services for HIV/AIDS patients should therefore apply a biopsychosocial or psychoneuroimmunology perspective to approach their clinical tasks.

2. Sexual behavior and immunity

How is the CD4, viral load and immunity linked to sexual behaviors by the HIV infected persons is still not well scrutinized in this study, although some of them did provide preliminary personal comments. Future studies should make a more focused analysis to elucidate the cognitive profile in this aspect, which can make significant contribution to understand the role personal belief can impact on the prevention of further transmission of HIV from the HIV infected persons.

3. Triad relationship

Triad relationship does exist in remedies utilization, while it lacks for triad interaction among stakeholders, especially between physicians and CAM practitioners.

4. The confidence in HAART and the use of complementary and alternative medicines

In any condition, most of the respondents followed the top principle of adhering to HAART regimen. Other types of therapies were used to complementary to rather than replace with HAART, mainly for purposes of relieving the discomforts or disorders resulted from the regimen. The CAM use should be an issue for future health education and counseling for HIV patients and, even more importantly, for the training programs targeting on health professionals.

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