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Experiences of patients with HIV/AIDS receiving mid- and long-term care in Japan: A qualitative study

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ABSTRACT

Purpose: In the era of antiretroviral treatment (ART), treatment of HIV has become more manageable, and most patients with HIV benefit from long-term therapy in Japan. The aim of this qualitative study was to examine the experiences of patients with HIV/AIDS receiving mid- and long-term care in Japan. **Methods:** A qualitative study was performed using semi-structured interviews at an outpatient clinic of a university hospital in the Greater Tokyo area. A total of 31 Japanese patients with HIV who had been receiving treatment for at least a year were interviewed in Japanese. Data from these interviews were analyzed by ‘content analysis’ (Krippendorff, 1980).

Results: The data were organized into the following seven themes: “feelings toward diagnosis of HIV infection”; “perceptions and behavior after diagnosis of HIV”; “attitudes toward HIV therapy”; “fear and hope for the future”; “feelings toward professional support”; “life changes after HIV therapy”; and “struggles in relationships with others”.

Conclusions: Some participants accepted themselves as HIV-positive, some did not when they were diagnosis. This difference of reaction had effect on attitudes toward HIV therapy. But all participants continued mid- and long-treatments owing to feeling well and receiving support from professionals. Additionally, it found that patients were felt stigma of HIV-positive similarly to another Asian countries. Therefore, we should provide the entire Japanese society with knowledge about HIV/AIDS and be early and constant intervention by professional teams after being infected.

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1. Introduction

In the era of antiretroviral treatment, HIV is controllable but most HIV patients in Japan still benefit from long-term therapy. On the other hand, HIV patients are forced to live with physical, social and psychological problems caused by frequent medical visits and taking medication over the long-term, as well as discriminatory attitudes toward HIV/AIDS. These problems negatively impact

patients' lives because they develop a sense of alienation and feel discriminated against and controlled by medication throughout their treatment. Most patients struggle to deal with the stigma caused by HIV/AIDS and the other difficulties associated with this disease. It is important for patients to adjust their lifestyle to the disease and treatment in order to continue receiving treatment over the long-term and to avoid drug-resistance. In addition, in a study by Côté [1], HIV-infected long-term nonprogressors were not able to receive enough social support. Therefore, nurses have to support HIV patients who will receive treatment over the mid- and long-term not only physically, but also psychologically and psychosocially.

To date, some studies on the experiences of HIV patients have been conducted. However, most focused on patients living in developing countries and rural areas [2–5] and on nurses [6]. Since the experiences of HIV patients are greatly affected by their cultural background and environment, studies on the experiences of HIV

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patients living in Japan would be very useful in terms of thinking about nursing support. However, as noted by Matsuyama [7], only two studies focusing on the role of nurses in the long-term care of HIV patients and the impact of HIV on the lives of patients have been conducted in Japan since 2003. Moreover, the participants of some studies were HIV/AIDS patients at the time of diagnosis and soon after diagnosis, but no studies were found regarding the difficulties and problems that patients experience over the mid- and long-term course of treatment.

Accordingly, the aim of this study was to examine the experiences of HIV patients who receive mid- and long-term care in Japan.

2. Methods

2.1. Design

A qualitative descriptive design was used to examine the experiences of HIV patients who receive mid- and long-term treatment.

2.2. Participants

Participants were outpatients and inpatients at the outpatient clinic of one university hospital in the Greater Tokyo area who had been receiving HIV treatments for at least 1 year.

2.3. Data collection

The researchers conducted semi-structured interviews in Japanese with patients visiting a doctor or staying in the hospital between July 2011 and March 2012. All interviews were conducted in a private room in an effort to protect participants' privacy. Only patients who agreed to participate in the study were interviewed. The interview guide used in these interviews consisted of the following eight questions:

1. When your doctor said that you are HIV-positive, how did you feel?
2. Currently, what do you think of HIV/AIDS and HIV/AIDS treatment?
3. Since you started HIV/AIDS treatment, what have you had trouble with?
4. Since you started HIV/AIDS treatment, what are some good things that have happened?
5. After you started HIV/AIDS treatment, did your daily life change?
6. Currently, do you have a supportive driving force?
7. When did you need the support of health care professionals?
8. What kind of support did you need then?

All interviews were recorded and transcribed for analysis.

2.4. Data analysis

Data from the interviews were analyzed by content analysis following Krippendorff [8]. This method consists of the two-step described below.

2.4.1. Step 1: separate analysis

The transcripts were read thoroughly to acquire meanings from the words of each participant. The researchers extracted the context of each participant's thoughts and behaviors regarding HIV/AIDS and treatment from the transcripts making every effort not to change meanings. The extracted contexts were described in simple

sentences, after which they were labeled as "record units". In addition, "codes" were used to integrate the collected record units into exhaustive descriptions.

2.4.2. Step 2: pooled analysis

The researchers collected the generated codes created in Step 1 and integrated them into exhaustive descriptions, and then grouped similar descriptions into "categories". Moreover, "themes" were used to integrate the collected categories into exhaustive descriptions.

To enhance the reliability of this analytical procedure, the researchers calculated the rate of concordance by reanalyzing each other's coding. The rate of concordance was 0.621. Moreover, to enhance the validity, the authors, who consisted of skilled nurses in HIV/AIDS care and researchers with ample experience in HIV/AIDS nursing and qualitative research, consulted throughout the analysis process.

2.5. Ethical considerations

This study was approved by the Ethics Committee of Yokohama City University Hospital, Yokohama City, Japan. The researchers received written informed consent from all participants before conducting interviews. Moreover, data from each interview were used only after obtaining the permission of the participant.

3. Results

3.1. Demographic characteristics

Thirty-one patients who were judged to be clinically stable enrolled in our study. The participants included 30 men and one woman. Their ages ranged from 34 to 72 years with an average age of 51.29 years. Table 1 shows the demographic characteristics of the participants.

3.2. Experiences of patients with HIV/AIDS receiving mid- and long-term care in Japan

Thirty-eight categories emerged from the data, integrated into seven themes: "feelings toward HIV diagnosis"; "perceptions and behavior after HIV diagnosis"; "attitudes toward HIV therapy"; "fear and hope for the future"; "feelings toward professional support"; "life changes after HIV therapy"; and "struggles in relationships with others".

For themes and categories highlighting qualitative findings are shown in Table 2.

3.2.1. "Feelings toward HIV diagnosis"

This theme included the following four categories: "found out about HIV infection by making a blood donation, getting pregnant or feeling symptoms", "shock at my own HIV infection", "predicted my own HIV-positive status" and "disagree with my HIV infection".

All participants thought about their HIV-positive status a lot when they first heard their diagnosis. Some participants found out about their HIV infection by making a blood donation, getting pregnant or having symptoms related to HIV such as hepatitis or Pneumocystis pneumonia (PCP). Related to this, one participant who got PCP said:

I could barely think about anything. "Can I carry on working?", "How much is treatment for HIV/AIDS going to cost?" and "I wonder if I will die before too long?" I thought such things.

In addition, most participants were shocked to hear of their HIV infection and disagreed with their HIV-positive status because they

Table 1
Demographic characteristics of participants. (n = 31).

| Sociodemographic variables | n (%) |
|--------------------------------|-------------|
| Gender | |
| Men | 30 (96.8) |
| Women | 1 (3.2) |
| Ethnicity | |
| Japanese | 31 (100) |
| Duration of illness | |
| 1–4Y | 13 (41.9) |
| 5–9Y | 14 (45.2) |
| Over 10Y | 4 (12.9) |
| Duration of medication | |
| 1–4Y | 17 (54.8) |
| 5–9Y | 11 (35.5) |
| Over 10Y | 3 (9.7) |
| Change in therapy | |
| Yes | 19 (61.3) |
| No | 12 (38.7) |
| Occupation | |
| Yes | 21 (67.7) |
| No | 10 (32.3) |
| | Mean ± SD |
| Age (Years) | 51.3 ± 11.3 |
| Duration of illness (Years) | 6.0 ± 3.0 |
| Duration of medication (Years) | 5.07 ± 2.9 |

had not expected such a diagnosis and HIV/AIDS has the image of being a permanent disease. On the other hand, some participants foresaw their HIV-positivity from their past behavior.

3.2.2. "Perceptions and behavior after HIV diagnosis"

This theme included the following six categories: "change in perception of HIV", "feel at ease after receiving information about HIV/AIDS", "feel justified in HIV diagnosis", "pay attention to my increased susceptibility to infection", "not want anyone to know about my HIV-positive status" and "get HIV off my mind."

Some participants changed their perception of HIV and got HIV off their minds in order to come to terms with their diagnosis. Additionally, some participants mentioned they did not want anyone to know about their HIV-positive status because of the social stigma attached to HIV/AIDS therapy and HIV-positivity. One participant commented:

I disguised anti-HIV drugs in my wallet and took pills while no one was looking. I struggled with taking the medicine. For example, when I went to the restroom, I took pills.

On the other hand, some participants found it easy to accept their HIV diagnosis, commenting that they felt justified in the diagnosis. Also, some participants commented they paid attention to their increased susceptibility to infection. One participant finally felt at ease after receiving information about HIV/AIDS when he had side effects. This participant stated:

Actually, I experienced side effects. And I thought, "I may be having side effects." The reality was a less serious matter than I expected.

3.2.3. "Attitudes toward HIV therapy"

All participants talked about their attitudes toward HIV therapy. The theme of "attitudes toward HIV therapy" included the following ten categories: "live a stable life by adhering to therapy", "abandon myself to despair after HIV diagnosis", "burdens of therapy", "change the therapy because of drug resistance and side effects", "hate to change the therapy even if I have side effects", "be

afraid of decreasing oral medications", "suffer from a sense of isolation", "side effects calm down with changes in therapy", "cannot ensure oral medications will be taken correctly" and "live with no purpose".

These categories were split into negative and positive attitudes related to HIV/AIDS therapy. The negative categories were associated with social isolation, risk of drug-resistant viruses and side effects. Two participants who felt isolation said:

If I were off the medication, I would die shortly after treatment interruption. I thought "That's OK." When I was out of medicine, I might want to die if that situation continued.

Because HIV is a disease I would not talk about in public, it is the hardest thing. I feel it would be easier to talk to others about a disease that is more serious than AIDS.

The positive categories were associated with relief and the disappearance of side effects and symptoms related to HIV/AIDS through the effects of treatment. Related to this, two participants commented:

I have a reliable livelihood after beginning treatment. I think my condition could not be worse because of taking this anti-HIV medication.

I treated HIV as a chronic disease because I have mild symptoms. I appreciate it. The side effects have partially stabilized, and so far I have not caught a cold.

3.2.4. "Fear and hope for the future"

This theme included the following three categories: "expect medication to give a full recovery", "worry about the future" and "concern about getting checked by a doctor other than the primary care doctor". Some participants expected medication to lead to recovery and some worried about the future. One participant who experienced fear mentioned:

I am anxious about my old age. I will develop dementia, take too many drugs. When it comes time for me to need help with living daily life, I would be refused care by a helper. I would not know what to do.

3.2.5. "Feelings toward professional support"

All participants had positive, negative, or both feelings toward professional support. The theme of "feelings toward professional support" included the following three categories: "feel indignant toward medical staffs' attitudes", "seek the help of medical professionals" and "appreciate public support". Most participants felt a sense of ease with professional support from doctors, nurses and social workers, and expressed appreciation for them. One participant commented:

I would be afraid after my doctor has gone. I hope the doctors and nurses remain unchanged and stay with me. I am lost without a secure place.

On the other hand, one participant felt anger towards doctors and explained:

My doctor talked to an industrial doctor about my HIV without my permission. So he knew it. The doctor called him and did not apologize to me. I am disappointed and do not understand why he told someone else about my HIV.

Table 2
Experiences of patients with HIV/AIDS receiving mid- and long-term care in Japan.

| Theme | Category |
|--|--|
| Feelings toward HIV diagnosis | <ul style="list-style-type: none"> · found out about HIV infection by making a blood donation, getting pregnant or feeling symptoms · shock at my own HIV infection · predicted my own HIV-positive status · disagree with my HIV infection |
| Perceptions and behavior after HIV diagnosis | <ul style="list-style-type: none"> · change in perception of HIV · feel at ease after receiving information about HIV/AIDS · feel justified in HIV diagnosis · pay attention to my increased susceptibility to infection · not want anyone to know about my HIV-positive status · get HIV off my mind |
| Attitudes toward HIV therapy | <ul style="list-style-type: none"> · live a stable life by adhering to therapy · abandon myself to despair after HIV diagnosis · burdens of therapy · change the therapy because of drug resistance and side effects · hate to change the therapy even if I have side effects · be afraid of decreasing oral medications · suffer from a sense of isolation · side effects calm down with changes in therapy · cannot ensure oral medications will be taken correctly · live with no purpose |
| Fear and hope for the future | <ul style="list-style-type: none"> · expect medication to give a full recovery · worry about the future · concern about getting checked by a doctor other than the primary care doctor |
| Feelings toward professional support | <ul style="list-style-type: none"> · feel indignant toward medical staffs' attitudes · seek the help of medical professionals · appreciate public support |
| Life changes after HIV therapy | <ul style="list-style-type: none"> · life will not go the way I want because of physical deterioration · adjust my lifestyle to treatment · feel conflicted about adjusting my lifestyle · take oral medication to live · realize the benefits of therapy · therapy does not have an impact on my lifestyle · adjust therapy based on my own judgment depending on my lifestyle |
| struggles in relationships with others | <ul style="list-style-type: none"> · suffer from relationships with others because of HIV-positive status · seek connectedness to others with the same disease · worry about having a partner with the same disease · appreciate the people around me who were supportive · be careful not to pass infection on to others |

3.2.6. "Life changes after HIV therapy"

Most participants had to change their lifestyle after starting HIV therapy. The theme of "life changes after HIV therapy" included the following seven categories: "life will not go the way I want because of physical deterioration", "adjust my lifestyle to treatment", "feel conflicted about adjusting my lifestyle", "take oral medication to live", "realize the benefits of therapy", "therapy does not have an impact on my lifestyle" and "adjust therapy based on my own judgment depending on my lifestyle". Some participants regarded life changes after therapy as major, while others did not. One participant who experienced a major change mentioned:

When I think back, I minded having to continue taking medications all my life. I have very little choice. Now I am not a burden to it.

3.2.7. "Struggles in relationships with others"

Most participants mentioned interactions with others. The theme of "struggles in relationships with others" included the following five categories: "suffer from relationships with others because of HIV-positive status", "seek connectedness to others with the same disease", "worry about having a partner with the same disease", "appreciate the people around me who were supportive" and "be careful not to pass infection on to others". Some

participants sought relationships with others, and some did not. One participant who sought relationships with others said:

I am glad to hear the stories of others with the same disease. Someone tell me what to do, someone tell me what happened at times like this. I am greatly encouraged by it.

On the other hand, one participant who suffered from lack of a connection to others commented:

Since I got a disease, I think about a lot of things. For example, I hold HIV in my mind. I am afraid of someone finding out about my disease. So I want to keep to myself.

4. Discussion

4.1. Problems faced by Japanese patients with HIV/AIDS who receive mid- and long-term care

Some participants accepted their HIV-positive status, whereas others showed negative reactions such as disagreeing with their diagnosis upon first hearing it. In cases of negative reactions, some kept their HIV-positive status a secret, took their medications privately, and suffered since diagnosis. On the other hand, receptive participants could gather information themselves and live free

from anxiety when they experienced side effects. Moreover, some of the negative participants felt socially isolated and like they were living with no purpose, and some were driven to desperate acts such as deciding to discontinue treatment on their own. Although most of the participants in this study were male, phenomenological research of women infected with HIV shows that women appear to experience big changes in their lives after receiving a HIV-positive diagnosis [9]. In this study, we did not observe any specific gender bias in the experiences of HIV/AIDS patients. However, we have to be aware that each patient's reaction to receiving mid- and long-term treatment is related to their attitude toward therapy and continued treatment, and deal with each individual patient accordingly.

On the other hand, all participants were patients with HIV/AIDS who had been undergoing treatment for over 1 year. Even those who had decided to temporarily discontinue treatment on their own had resumed therapy at the time of the interviews. In addition, even if patients showed negative reactions when they heard they were HIV-positive, they continued therapy because they actually felt well and received support from professionals knowledgeable about HIV/AIDS. Therefore, we should support patients not only temporarily, such as when they first hear they are HIV-positive, start treatment or change the therapy, but continuously over the course of their disease.

Patients with HIV/AIDS receiving mid- and long-term care have to adjust their lifestyles. Patients who are working need to regulate their schedules and take medications as prescribed, and this requires a large amount of effort. Swendeman [10] states self-management for HIV and other chronic diseases has three dimensions, physical, psychological and social. Similarly, we suggest it is important for health care professionals to help HIV patients receiving mid- and long-term care work on these aspects by monitoring their health status (e.g. CD4 count and symptoms of AIDS), and providing psychological and social support for reconciliation of continued treatments, family life and career.

Currently in Japan, based on a 1993 notification from the Ministry of Health and Welfare, special treatments for HIV/AIDS are managed at designated hub hospitals, central hub hospitals and district blocks of hub hospitals. Since 2006, these hospitals have implemented certain standards for HIV/AIDS treatment consultancy costs [11]. There is, however, great variation in the quality of HIV/AIDS care among hospitals that provide HIV care, such as differences in staffing and equipment [12]. Although Japan has implemented various social supports for HIV/AIDS patients, including a physical disability certificate for immune dysfunction due to HIV, HIV/AIDS care in Japan is experiencing a shortage of human resources, making it difficult for patients to gain information. Enhancement of the support system for professional teams involved in HIV/AIDS care is greatly needed to enable patients to continue therapy.

Because the participants of this study were HIV/AIDS patients who went to a central hub hospital for HIV/AIDS in the Greater Tokyo area, we were able to obtain information about the professional support provided by social workers, nurses and doctors. Some participants felt indignant about this support and expressed outrage over being told of their HIV infection by a doctor not at a hub hospital, but another hospital. Therefore, we suppose that professionals' responses can prevent patients from seeking specialized treatments. In order to encourage patients to receive HIV treatments, hub hospitals for HIV/AIDS should enhance cooperation with other hospitals. A previous study on caregiving and social networks in Canadian HIV patients [13] stated that health care professionals need to pay special attention to HIV patients as a disadvantaged and stigmatized group among chronic diseases patients. Health care professionals should also provide care to

increase self-management by patients, construct a system of medical cooperation, and pay attention to HIV/AIDS patients receiving treatments.

Appropriate treatment for HIV/AIDS helps prolong the lives of patients. On the other hand, some patients have suffered from stigma and discrimination associated with HIV and other sexually transmitted diseases (STDs) as well as sexual orientation for a long time. Because it is not well known among the general public in Japan that HIV/AIDS is controllable and HIV/AIDS generally has the image of being an STD commonly found among homosexuals, HIV/AIDS patients are socially isolated and can drift away from their families. Moreover, HIV/AIDS patients who need home care face many difficulties in receiving support from both their families and professionals, and are often refused care by a primary care doctor. The stigma felt by HIV/AIDS patients is a major issue in Japan and other Asian countries, as found in a study on scale development of HIV stigma in Asians living with HIV [14] and a study on HIV stigma in patients in south central China [15]. Our findings showed some participants suffered from troubled relationships with their families and others and want to have a relationship with fellow patients. They paid attention to their relationships with others, such as taking care not to pass infection to others. In order to continue therapy, it is preferable that patients communicate to key persons in their lives, such as their family and partner, that they are HIV-positive. Professionals should support patients in communicating their HIV-positive status to others. Furthermore, some health care professionals and care staff lack knowledge of HIV/AIDS; thus, patients are currently being denied medical attention and care services other than specialized HIV/AIDS care. The stigma that HIV/AIDS patients feel is different from other chronic diseases such as hypertension and diabetes. We should offer information and expertise about HIV/AIDS to professionals and Japanese society as a whole to relieve HIV stigma and enable patients to continue HIV/AIDS therapy.

4.2. Implications of nursing

Based on the results of this study, professional teams in HIV/AIDS care should provide early intervention for patients after diagnosis. Since patients have to receive prolonged HIV treatments, professionals should provide support that helps them adapt treatments into their daily lives to make it possible to stay on treatments. According to a study on the health needs of people living with HIV/AIDS [16], HIV patients require prevention and counseling services for vulnerable groups, diagnostic and treatment services by professionals, and rehabilitation services. To approach these needs of HIV patients, nurses should collaborate closely with social workers, dieticians, the government, and doctors. Nurses can see patients from a wider perspective that includes aspects of their personal and social lives and therapy, and play coordinating roles on a professional team that supports patients. A qualitative study in Japan [17] found that nurses played a role in coordination and management with other health care professionals as the hub of a medical care team providing HIV/AIDS care. In other words, nurses exploit their abilities to the fullest when providing HIV/AIDS care. Moreover, to deal with the stigma and feelings of isolation that HIV/AIDS patients experience, HIV/AIDS professional teams, including nurses, should provide care facilities and health care workers accepting HIV/AIDS patients who need care, local residents and patients' families with knowledge about HIV infection. By doing this, HIV/AIDS patients will be more readily accepted by others. As it is more difficult for HIV/AIDS patients to talk with others about their sexuality compared with those with other chronic diseases, nurses can tailor a way for them to meet and talk to other patients with similar experiences, such as patient advocacy groups and peer

counseling. Nurse-led professional teams enable patients to receive treatments early after being diagnosed with HIV.

Finally, we clarified when professionals should intervene and the implications for how they can support patients. In the future, we should develop a support program to tailor treatments to patients' daily lives and intervene early and continuously in groups at high risk of treatment interruption. We expect our findings to contribute to the development of such a support program.

4.3. Limitation of this study

This study had several limitations that should be recognized. One limitation is that this was a single-site study and participants consisted of outpatients and inpatients at a central hub hospital for HIV/AIDS treatment in the Greater Tokyo area. Specifically, with regards to professional support, this hospital may be different from other hospitals with an HIV/AIDS care unit. Another limitation is that over 90% of the participants were men. In the future, we should conduct a multi-site study and increase the number of participants to achieve a more even gender distribution.

5. Conclusions

Our results showed some patients accepted themselves as HIV-positive when they first heard of their diagnosis, whereas others did not. This difference in reaction affected patients' attitudes toward HIV therapy. All participants, however, continued mid- and long-term treatments because they actually felt well and received support from professionals in HIV/AIDS care. Additionally, we found that Japanese patients felt stigmatized because of their HIV-positive status and sexual orientation similarly to other Asian countries, and development of HIV therapy should address the long-term suffering caused by this stigma. Due to health care professionals' and care staff's lack of HIV knowledge, it was difficult for patients to receive primary care and care services. This sheds light on a major difference between HIV patients and patients with other chronic diseases who require mid- and long-term treatment. Therefore, we should provide Japanese society as a whole with knowledge about HIV/AIDS, and professional HIV/AIDS teams should provide early and constant intervention immediately after diagnosis.

Author contributions

IMAZU contributed to the conception and design of this study; IMAZU, MATSUYAMA, TAKEBAYASHI, MORI, and WATABE performed content analysis and drafted the manuscript; and WATABE critically reviewed the manuscript and supervised the whole study process. All authors read and approved the final manuscript.

Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

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