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# Difficulties and Coping Strategies Experienced by Employed People with HIV in Japan: A Qualitative Study Comparing High and Low Sense of Coherence Groups

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Additional information is available at the end of the chapter

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## Abstract

People with HIV experience anxiety about discrimination in the workplace and disclosing their disease. Effective coping ability toward HIV-related challenges may be associated with a person's sense of coherence (SOC). This study describes the range of difficulties HIV-positive individuals experience and their coping strategies, especially in the workplace. The experiences of those with high and low SOC are compared. Data were collected in Japan from 2007 to 2009 using a qualitative approach. Semistructured interviews were conducted with 40 participants with HIV with work experience. Interviews focused on individual's perspectives, including self-perceptions of physical and mental functioning, work conditions, and perceived changes in their circumstances. Participants were divided into high and low SOC groups based on SOC-13 scores. A number of categories and subcategories of experiences were extracted, including "acute feeling of the severe social positioning of HIV," with some categories specific to those with low SOC. Those with high SOC appeared to have a unique perspective that supported more successful coping, for example, "Awareness of death is linked to valuing living in the present," "Do not be discouraged by uncertainties and difficulties," and so on. It suggests that development of coping skills may help people with HIV.

**Keywords:** coping strategies, qualitative study, salutogenesis, sense of coherence, Japan

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## 1. Introduction

Acquired immunodeficiency syndrome (AIDS) is characterized by infection with human immunodeficiency virus (HIV) and serious, systemic dysfunction of immunity. Although its global incidence rate is declining, the rate of HIV infection is increasing in Japan, reaching approximately 16,000 cases in 2014 [1]. In the last decade, new treatments for HIV infection and AIDS have improved health and life expectancy for many people who are HIV-positive. In the recent era of highly active antiretroviral therapy, the estimated median survival for a young person diagnosed with HIV infection is >35 years [2]. Most people with HIV are in a stable and manageable condition [3], with this group accounting for the majority of people infected with HIV in Japan, particularly males aged 20–40 years. For this group, infection was diagnosed at a time critical for career development [1].

The importance of employment has been emphasized in many studies on chronic diseases [4]. Employment helps people to function as adults and find self-worth, therefore playing an important role in maintaining human dignity [5]. Mental health is reported to be better in people with HIV who are employed than in those who are unemployed [6]. However, in the workplace, people with HIV suffer from anxiety about discrimination and layoff [7]. Disclosing the name of their disease may also be highly problematic for them [8, 9].

In many life situations, people with HIV experience various stressors [10]; for example, HIV is perceived as a more stigmatized disease than cancer [11]. People with HIV are also faced with problems unique to HIV, which further affect their vulnerability and makes psychological adjustment more difficult [12]. People with HIV are, therefore, forced to cope with highly stressful situations, brought about by stigma and their own anxiety about experiencing stigma.

Sense of coherence (SOC), a concept proposed by the health sociologist Antonovsky, was conceptualized and standardized as the ability to cope successfully [13]. SOC focuses on salutary factors (i.e., health factors) described as “salutogenesis” [14]. Rather than focusing on pathogenesis, or a conventional medical line of questioning regarding the causes of disease, salutogenesis aims to shed light on what creates health.

Antonovsky created the salutogenic model, which illustrates relationships among stressors, coping (tension coping and coping resources), and SOC. The salutogenic model comprises two theoretical models. First, in the face of stressors and the resulting strain, SOC copes by mobilizing generalized resistance resources. The success or failure of coping depends on the richness of coping resources and the strength of SOC. The second theoretical model explains that SOC is formed by good life experiences and strengthened by successful experiences of coping with tension. The quality of these good life experiences is formed by “generalized resistance resources” (GRRs) [13]. GRRs can be identified as resources bound to an individual’s capacities and include material and nonmaterial qualities ranging from individual level factors to those of the person’s culture and/or society [15]. That is, GRRs are the physical, biological, artifactual-material, cognitive, emotional, valuative-attitudinal, interpersonal-relational, and macro-sociocultural characteristics of an individual or a group that are effective in avoiding or combating a wide variety of stressors [14].

The salutogenic model indicates that success or failure of stress coping depends on the level of SOC. Higher SOC brings more successful coping, which results in further strengthening SOC. Therefore, a positive spiral relationship has been suggested between SOC and successful coping experiences. In other words, high SOC helps stress coping, which promotes redefinition and reconstruction of the experience, creating a virtuous cycle [14, 15].

Describing coping experiences of people with high SOC is to describe successful coping with stressors. It is also important to describe how flexibly and successfully those with high SOC are able to cope. This may lead to useful suggestions for supporting people with HIV. In addition, comparing different coping styles of people with HIV who have high or low SOC, and examining their unique experiences and living environments may provide clues to their different perspectives and coping behaviors. Particular difficulties experienced by a person with HIV may also be related to low SOC or a decline in SOC.

There is a lack of information on the appropriate types of workplace support for people with HIV in the workforce. The present study aimed to describe the difficulties and coping strategies experienced by people with HIV in the workplace and compare the experiences of those with high and low SOC using the 13-item SOC scale [16]. It is anticipated that the results may provide clues to appropriate types of workplace support for people with HIV.

## **2. Method**

### **2.1. Study design**

Antonovsky stated that qualitative studies are useful to better understand the function of SOC, including its strength and flexibility [13]. The present study wanted to examine participants' experiences from their perspectives and analyze their work life from a new standpoint based on the salutogenic model. A qualitative approach was considered appropriate for these goals.

### **2.2. Participant recruitment**

First, medical facilities with specialized HIV outpatient clinics in Tokyo were asked to invite patients to participate in the study; 15 patients were recruited in total. Inclusion criteria were patients in their twenties to early fifties whose symptoms had been stabilized and who had work experience. Participants were recruited by nurses when visiting the facilities for treatment. Participants chose where the interviews took place, with most taking place at the medical facilities. NPO corporations and social welfare corporations were also contacted and asked to assist with recruitment of participants, and a further 25 participants were recruited. This second round of recruitment increased the diversity of the sampling routes as access to participants living in different areas (Kansai and Kyushu) was made possible. Three pilot interviews and the first 15 interviews for the present study were conducted by two interviewers. The interviewers were the first author and a researcher with a medical degree (Seiko Ishiuchi-Ishitani, fifth author) who was familiar with the interview questions and had worked as a special consultant for a social welfare corporation offering assistance to people with HIV. These interviews were conducted by two interviewers because the purpose of the present study was

to collect explorative data, and it was considered beneficial to observe participants from multiple angles. It was also thought that the presence of an interviewer who was affiliated with a social welfare corporation assisting people with HIV may give participants a sense of security and facilitate development of rapport. The 25 interviews in the latter half of the study were conducted by the first author only. The question items were more narrowly focused and based on the earlier data, and as participants introduced by the medical facilities were cooperative, no problems arising from one interviewer were anticipated. During the analysis of participant interviews, it became clear that the results would need to be further evaluated depending on infection route (homosexual contact, heterosexual contact, and tainted blood products), sex, type of employment (regular or irregular), and progression to AIDS. Therefore, it was decided that throughout the study, interviews would cover people with diverse characteristics. As the majority of patients infected through homosexual contact were men, female patients and patients infected by tainted blood products were considered to have different experiences. Therefore, these patients were invited to participate at slightly higher rates than the actual infection rate. We stopped recruiting participants after the number of interviews reached 40, as this was deemed to have reached saturation. Participant details are shown in **Table 1**.

### **2.3. Data collection**

During recruitment and on the day of the interview, participants were assured of privacy through verbal explanations and in written documentation. Before their interview began, participants signed a consent form that included permission to record the interview. The interviews took place in situations where privacy was secured, such as conference rooms and training rooms at a library. The interview duration ranged from 40 to 135 min, with a mean duration of 75 min. Interviews were conducted from September 2007 to September 2009. The interview questions covered: participants' perspectives of their physical and mental functioning since HIV infection was identified, working conditions and the type of job at the time, reactions of people around them, disclosure of infection, relationship with a partner, what HIV means to them, whether their views about HIV and feelings about life and work had changed, what kinds of change occurred, and how they evaluated these changes. The interview was particularly focused on participants' ways of thinking, asking "Why did you behave that way? (or not behave that way)"; "What does the experience mean to you?"; and "Why did you think that way?"

### **2.4. SOC scale**

We used the 13-item, 5-point version of the SOC scale, because the interviews were expected to take a long time and to allow comparison with survey data from a nationwide representative sample [16]. The reliability validity of SOC-13 Japanese edition was determined in a randomly selected nationwide sample of 1800 men and women aged over 20 years. The SOC mean for the sample was  $44.06 \pm 8.83$  [16].

### **2.5. Ethical considerations**

The first author has significant experience working as an occupational health nurse, as well as in supporting people who have a disease that is difficult to disclose to others; this breadth

	<i>n</i>	%
<b>Demographics</b>		
<i>Gender</i>		
Male	35	87.5
Female	5	12.5
<i>Age group</i>		
<30	5	12.5
30 ≤ 39	17	42.5
40 ≤ 49	15	37.5
50 ≤ 59	3	7.5
<i>Education</i>		
University, graduate school	18	45.0
Junior/high school and other	13	32.5
No answer	9	22.5
<b>HIV-associated indicators</b>		
<i>The length of time since HIV diagnose</i>		
<1 year	0	0.0
1–4 years	15	37.5
5–10 years	12	30.0
11 years and above	13	32.5
<i>Route of HIV infection</i>		
Tainted blood products and blood transfusion	5	12.5
Sexual contact	34	85.0
Unknown	1	2.5
<i>CD4 cell counts</i>		
200 ≤ 500/μl	19	47.5
500/μl ≤	21	52.5
<i>Sexuality</i>		
Heterosexual	10	25.0
Homosexual	24	60.0
Bisexual	6	15.0

**Table 1.** Demographic characteristics of participants (*n* = 40).

of experience enhanced understanding of the difficulties in interpersonal relationships in the workplace. After consulting with the facilities several times, careful consideration was given to the protection of privacy, participants' physical condition at the time of the interview, and arrangement of a comfortable interview place for participants. The purpose of the study,

methods, protection of privacy, and disclosure of the results were explained to participants orally and in writing. Participants were informed that they would be able to participate with a fictitious name, to ask any questions during the interview, would not have to answer if they did not want to, and would be able to stop participating at any point. Participants recruited through medical facilities were informed that the interviewer was not associated with the facilities and that their treatment would not be affected in any way, even if they withdrew from participation. The recordings, verbatim transcripts, and analysis notes were stored in a locked room, and the data were stored with real names and other personal information converted into codes. These materials could only be accessed with a password.

The present study was approved by the Medical Research Ethics Committee of Tokyo University, Graduate School (Approval No. 2403), and the Ethics Committee of the National Center for Global Health and Medicine (Approval No. 675).

## 2.6. Analysis

### 2.6.1. Interview data

The method of Lofland [17] was used to analyze interview data. First, a transcript of the interview was read repeatedly to grasp the whole picture of the interview. The information was then coded, categorized, and analyzed, with reference to the results of intergroup comparisons between participants with high and low SOC. To ensure the validity of the results, discussions and member checking were conducted with coresearchers [18].

### 2.6.2. Measuring SOC

SOC was measured after the interview. With the permission of participants, responses were collected while the interview was still being recording, and the majority of their responses were confirmed. According to Söderhamn is collect! [19], an official cut-off point is not prescribed for SOC, and the cut-off point differed in quantitative studies comparing high and low SOC [20, 21]. In qualitative research, the SOC score analysis cannot be conducted by performing group division. However, there is an exception in a study conducted in Croatia [22] that used the SOC-29 (7-point scale), which is the most commonly used version globally. In our study, we used the SOC-13 (5-point scale), as we intended to divide participants based on Japanese mean score. No previous research is available about group division of the SOC-13. Therefore, this was discussed among the present researchers while referring to a Japanese average score. Participants' average SOC-13 score was  $43.0 \pm 7.9$ . Given that the scale ranged from 13 to 60, this score was slightly higher than the nationwide sample average (the average score was 41.15 for those in their thirties and 42.16 for those in their forties) [16]. Based on the average score, median score, scores from previous studies, and the nationwide sample scores, participants scoring over 42 ( $n = 22$ ) were categorized as the high SOC group, with those scoring 39 or less ( $n = 12$ ) defined as the low SOC group. The remaining six participants scored 40–42 and were categorized as the middle SOC group.

### 3. Results

#### 3.1. Difficulties faced by participants

In the present paper, [ ] indicates a category, <<>> a sub-category, and <> a code. Relevant quotations from the interviews have been included to illustrate key themes. Details in parentheses after the quotations indicate the participant's ID number, sex, and SOC score (range 13–65).

Difficulties experienced by participants were divided into three domains: physical, social, and personal. Physical domain categories were [Awareness of death] and [Low possibility of maintaining one's physical condition]. Social (employment, interpersonal) domain categories were [Inability to maintain or weakening of coherence with respect to work], [Being made aware of the lack of understanding and knowledge about HIV in society], [Cut off from society because of the name of the illness], and [Keeping love and marriage at a distance]. The personal domain was represented by the categories [Feelings of guilt and self-reproach] and [Having complicated feelings about being infected]. No distinctive difficulties were observed in the high SOC group.

##### 3.1.1. Difficulties specific to patients with low SOC

Four distinctive subcategories found in the low SOC group were the following: <<Being at work becomes difficult after infection is determined>>; <<Leaving one's job due to the fear of HIV becoming known>>; <<Being seized by the idea that working hard has no meaning>>; and <<Just getting by is enough for my life>> (**Table 2**).

*I don't find any meaning in working so hard. To be honest, I just think it's enough to do whatever is in front of me. That's the only prospect I have at the moment. (#31, male, score: 33)*

Some participants in the low SOC group experienced [Being made to realize the lack of understanding and knowledge about HIV in society].

*During a job interview, people ask how I got the disease. My answer is "because I had sex without using a condom." They probably don't understand much about immunodeficiency, even people who want to hire people to whom the Disabled People Employment Promotion Act applies. (#9, male, score: 34)*

In the category [Cut off from society because of the name of the illness], participants in the low SOC group reported experiencing severe stigma, including: <<Being told that my handicap isn't normal>> and <<Being told that you don't get that disease if you live a normal life>>. Participants reported that stigma by people they were close to and had a good relationship with in the workplace or where they received treatment was most hurtful. This stigma was particularly felt when a participant was hired under the Disabled People Employment Promotion Act, and for some, this became a major reason to give up working.

*(As a worker covered by the Disabled People Employment Promotion Act) when I was having my individual counseling, the first thing they said was "we didn't want to hire you from the start." Loud and clear. Looking back now, the president of the company must have told them to hire me. They perhaps couldn't say no and hired me unwillingly. They even told me, "We wanted to employ a normal disabled person, so to speak." (#43, male, score: 28)*

Domain	Categories	Subcategories Difficulties peculiar to patients with low SOC
Physical	[Awareness of death] [Low possibility of maintaining one's physical condition]	
Social (employment, interpersonal)	[Inability to maintain/weakening of coherence with respect to work]	<<Being at work becomes difficult after infection is determined>> <<Leaving one's job due to the fear of HIV becoming known>> <<Being seized by the idea that working hard is no meaning>> <<Just getting by is enough for my life>>
	[Being made to realize the lack of understanding and knowledge about HIV in society] low SOC only	<<Being asked that why you were infected>> <<Being asked the meaning of immune dysfunction>>
	[Cut off from society by virtue of the disease's name]	<< Being told that my handicap isn't normal>> <<Being told that you don't get that disease if you live a normal life>>
	[Keeping love and marriage at a distance]	<<Arguments about who gave who the infection with partner>>  <<A poor relationship with a lover or a partner>>
Personal	[Feelings of guilt and self-reproach] [Having complicated feelings about being infected]	<<Victims who had been infected by someone else>> <<Anger towards the person who passed on the infection>>

**Table 2.** Difficulties experienced by participants

Besides difficulties at work, participants experienced anguish on an interpersonal level about disclosure of their infection to significant others and about lovers and marriage. Particularly in the low SOC group, participants felt there were <<Arguments about who gave who the infection>> which led to <<A poor relationship with a lover or a partner>>, and as a result they (sexually infected homosexual males) experienced [Keeping love and marriage at a distance].

*The person I was going out with had shingles twice in a row. Then I thought I could also have it (HIV) and so I checked. He probably gave it to me, but he didn't tell me anything. In the end, I lost my trust in him and we broke up. (#31, male, score: 33)*

Participants expressed [Feelings of guilt and self-reproach] for having become infected; particularly, participants in the low SOC group felt very strongly that they could not understand and accept why they had been infected. As a result, they perceived themselves as <<Victims who had been infected by someone else>>. This feeling of being a victim was linked to <<Anger towards the person who passed on the infection>> who they felt was to blame.



*I trusted the pitcher (the person who inserts his penis) and didn't wear a rubber. That's how I got it, and the guilty party, so to speak, was my partner and he is responsible. I can't forgive him for that.*  
(#43, male, score: 28)

### 3.2. Characteristic coping experiences in the high SOC group

Coping experiences characteristic of the high SOC group are presented in **Table 3**.

These experiences were classified by encounter environment and way of coping. In terms of the environment, employment and personal relationships were extracted as categories in the social domain. Coping may also be classified as being cognitive or behavioral.

#### 3.2.1. Social domain

In the category [A workplace environment enabling maintenance of coherence with respect to work], working conditions were important, such as access to a paid vacation and a fully equipped welfare system. Other important conditions were no shift work, preservation of privacy, minimal overwork, minimal other physical burdens, and stable work. In addition, <<A workplace climate appreciating diversity>> was important for men who have sex with men. This enabled them to continue doing the same job in the same way as before infection.

*In our corporate climate, people don't get involved with each other unless it concerns business. There are quite a few people who take sick leave in my company because of bad physical and mental condition. When they are back in the office, everyone behaves normally as though nothing special has happened.*  
(#39, male, score: 50)

The category [Opportunity to have a workplace where one is needed and where colleagues trust each other] reflected the importance of personal relationships in the workplace. One participant who became infected through sexual contact with another man commented on informing his superior of his need for leave of absence due to the infection.

*Since I was infected with HIV, my condition was bad and I decided to tell my superior. When I was about to tell him how I was infected, he said, "Take a rest" and "How you got the disease doesn't matter to me at all. You are still you and I understand very well how hard you have been working."* (#4, male, score: 49)

In this way, <<Having the confidence that even though infected, one is still trusted as a member of society>> provided substantial moral support.

The category [Had opportunity to know someone who understands about the infection] indicated understanding of HIV infection by significant others, such as parents and siblings, friends, lovers, and partners. Many participants commented on how, at difficult times, such as the onset of AIDS and when they lost their jobs, they had been helped by others who <<Offered comfort during times of physical and mental stress>>. Among their significant others, it was important that there were <<Friends who remained as close as they had been before hearing of the infection>> and <<Support from the company's occupational health doctor>> in the workplace. However, only participants who were hired because of a disability or who had hemophilia told their company's occupational health doctor about their disease. Even if the company's occupational health doctor said they were thorough about

Domain	Categories	Subcategories	Coping characteristics
Social (employment, personal relationships)	[A workplace environment enabling maintenance of coherence with respect to work]	<<A workplace climate appreciating diversity>>	Coping with the environment they encounter
	[Opportunity to have a workplace where one is needed and where colleagues trust each other]	<<Having the confidence that even though infected, one is still trusted as a member of society>>	
	[Had opportunity to know someone who understands about the infection]	<<Offered comfort during times of physical and mental stress>> <<Friends who remained as close as they had been before hearing of the infection>> <<Support from the company's occupational health doctor>> <<No change in love and affection from spouse, lover or partner after informing them of the infection>>	
	[The infection provided an opportunity to build/rebuild important bonds]	<<building relationships with significant others as a result of infection>> <<Infection led to meeting irreplaceable people>>	
	[No perception of direct stigma]	<<The attitude was the same as that towards other disabilities>>	
	[Treat the infection and related events neutrally]	<<Being infected is unlucky but not a disaster>> <<Apart from the infection, I'm happy so it's OK>> <<Everyone faces their own difficulties and anxieties>> <<Is the problem really caused by HIV?>>	Cognitive coping
	[Awareness of death is linked to valuing living in the present]	<<Think about what kind of work I really want to do and how to live>>	
	[Judging and assessing events from a long-term point of view]	<<Particular events in the past resulted in me being in this position now>>	
	[Create boundary lines for important things, do a reality check, and then actively change them]	<<Reaching a compromise between the content and conditions of work and one's physical condition and or environment>> <<Changing one's work goals and aim in life>>	

Domain	Categories	Subcategories	Coping characteristics
	["Anyway, give it a try" behavior]	<p>&lt;&lt;Disclosed the infection to a partner or lover in an attempt to have them accept it&gt;&gt;</p> <p>&lt;&lt;Disclosure of the infection at the company to gain the support of superiors and colleagues at the workplace&gt;&gt;</p> <p>&lt;&lt;Disclosure of the infection to friends to confirm the way of socializing in the future&gt;&gt;</p> <p>&lt;&lt;Ask for help myself&gt;&gt;</p>	Behavioral coping
	[Do not be discouraged by uncertainties and difficulties]		Cognitive coping
	[Being infected cannot be helped and I am prepared for the worst]	<p>&lt;&lt;I accept responsibility for becoming HIV-infected (infection between homosexuals)&gt;&gt;</p> <p>&lt;&lt;I am not going to be at the mercy of anger due to the infection (harmful effects of medicines, heterosexual)&gt;&gt;</p>	
	[Ready to live one's own life]	<p>&lt;&lt;Live while regretting one's behavior that led to infection (homosexual infection)&gt;&gt;</p> <p>&lt;&lt;I will go straight&gt;&gt;</p> <p>&lt;&lt;Be thoroughly prepared for the onset of AIDS and dying before others&gt;&gt;</p>	

**Table 3.** Coping experiences observed in high SOC participants

protecting privileged information, many participants did not tell anyone in the company about their HIV infection.

*The drugs I was taking were no longer suitable for me and I really thought of suicide then. It took me about half a year to get settled, and my mother came regularly from my hometown to stay with me because she thought I shouldn't be left alone. She really helped me a lot. (#23, male, score: 49)*

Almost all participants felt they had to tell their spouse, lover, or partner about their infection to prevent them also becoming infected. In this situation, many participants in the high SOC group experienced <<No change in love and affection from spouse, lover, or partner after informing them of the infection>>. Some received considerable support from the presence of significant others who understood about HIV infection and continued to accept them.

*I have only dated two people since I found out about my disease. I would tell him/her about my condition (HIV) and ask if he/she is still sure. Interviewer: "And if he/she says it's OK, then the relationship could start?" I would feel that I should do my best for them. (#39, male, score: 50)*

The category [The infection provided an opportunity to build/rebuild important bonds] included the subcategory <<Rebuilding relationships with significant others as a result of infection>>. This was reflected by participants who reported that disclosing HIV infection improved their relationships with other people, particularly parents, siblings, and other blood relatives. Participants in the high SOC group experienced love and affection from their parents and siblings, and felt disclosing the infection provided a chance to rebuild relationships.

*Since our points of view have been always different, my brother and I weren't so close once we had both grown up. However, because he is younger, my brother was very understanding, and said "anybody could be infected." That changed my relationship with him completely. Now we are very close. If I hadn't been infected, things probably wouldn't have turned out this way. (#26, female, score: 53)*

Another subcategory, <<Infection led to meeting irreplaceable people>>, referred to those who felt lucky because they had met people they would never have met if they had not been infected. As well as attaching a more positive meaning to HIV infection, this was a source of energy for some participants to live with HIV and continue living.

*Then I met this man and realized that he loved me for everything, including my disease. I thought that even if I never go out with another man until I die, that's OK, because this experience was quite enough for me. Looking back now, I wouldn't have met this man who really loved me if I hadn't had my disease. As he said himself, to find each other I had to have been infected. We wouldn't have shared any common ground, otherwise. (#26, female, score: 53)*

The category [No perception of direct stigma] was common for participants in the high SOC group. These participants reported that regardless of the route of infection, when the name of their disease was disclosed when applying for a job open to disabled people, they experienced <<The attitude was the same as that toward other disabilities>>, and even if there was concern for their physical condition, the attitudes of people around them did not change.

*The top people of the company weren't prejudiced and the company's philosophy was to let more disabled people have jobs and participate in society. So, I thought I preferred to tell them and be employed. At the interview, they asked me, as they do normally, "Is there any difficulty when you work?" and "Do you visit hospital regularly?" and so on. I told them "There are no problems when I work because my condition is stable." (#10, male, score: 46)*

### 3.2.2. Cognitive and behavioral coping

#### 3.2.2.1. Cognitive coping

The category [Treat the infection and related events neutrally] reflected how participants in the high SOC group tended to view things objectively and look at them calmly from a distance. This was observed in the high SOC group, where even if participants experienced feeling guilty or depressed, they felt that <<Being infected is unlucky but not a disaster>>. When re-evaluating their current lives, they felt <<Apart from the infection, I'm happy, so it's OK>>. When comparing their past with the present, they thought about past hardships with the infection in the context of <<Everyone faces their own difficulties and anxieties>>.

Some participants also reported that when others knew of the infection, they sometimes reacted negatively. Even without experiencing strong stigma, this response made participants feel bitter, sad, or angry. However, those in the high SOC group reflected on the situation later and wondered <<Is the problem really caused by HIV?>>. They perceived hard experiences as not necessarily all being a result of HIV. They thought objectively about their own HIV infection and looked at themselves with a calm, neutral attitude.

*Well, it wasn't a friend of mine but an acquaintance of my spouse. She knew about my infection and someone told me that she was talking about me behind my back. Apparently, she said that she didn't want to have meals with me, or something. But of course, that isn't all about my disease. I reckon that's something to do with liking or disliking each other. Me being an HIV carrier is the excuse she uses. She probably just hated my personality (laughs). (#26, female, score: 53)*

The category [Awareness of death is linked to valuing living in the present] reflected how participants assumed there was a high possibility of dying prematurely. Those in the high SOC group were observed to live life to the fullest, do what they wanted to do now, and <<Think about what kind of work I really want to do and how to live>>.

*It's true that I can work harder since I got this disease. Before, when I was healthy, I had so little motivation. After I got ill, I became very grateful to my company. I became ill and they still employ me. They allow me to take leave, too. Then, I remembered that I really wanted to continue working because when I left my hometown, I made a strong resolution. (#37, male, score: 57)*

The category [Judging and assessing events from a long-term point of view] represented those who considered that <<Particular events in the past resulted in me being in this position now>> rather than making fragmentary judgments or assessments. Furthermore, they reported that "what I am experiencing now will be in some way useful in the future." Inevitably, perceiving that the past, present, and future are joined was linked to comments about belief in invisible powers such as "believing in fate" and "believing in God's will."

*I got this (HIV) and it had an influence on my field of specialization. I had to give up. I was disappointed, but somehow I was able to think positively that something good would turn up and that this infection must be useful for something in the future. Interviewer: "What made you think so?" I've always been like that. I think positively and believe in what I think (laughs). That's all. (#33, male, score: 44)*

The category [Create boundary lines for important things, do a reality check, and then actively change them] described how, for many participants, HIV infection led to letting go of things

that were important or giving up long-term dreams. This was particularly true for work. In the high SOC group, there were some who accepted this, coping by <<Reaching a compromise between the content and conditions of work and one's physical condition and/or environment>> and <<Changing one's work goals and aim in life>>. Being aware that decisions lie within oneself was particularly important. Even if the current situation involved unavoidable reconciliation, awareness that one must make the final decision alone, be confident, and make decisions independently was important.

*(Because of the infection, this person was transferred to a clerical position from working outside the office) I really wanted to continue the job I was doing until I had gained one year of experience. But, thinking about the trouble I might cause other people if I insisted on doing the former job, and the company's offer of allowing me to continue working, in the end I decided by myself that I should do my best in the new position. (#4, male, employed, score: 49)*

### 3.2.2.2. Behavioral coping

The category ["Anyway, give it a try" behavior] often applied when infection was disclosed to a lover or a partner. Nearly all participants in the low SOC group had given up the idea of having a lover saying, "After all, I can't make love" and "Nobody would understand." In contrast, participants in the high SOC group reported that they carefully planned the timing and <<Disclosed the infection to a partner or a lover in an attempt to have them accept it>>. This resulted in the relationship continuing in some cases and ending in others. Either way, participants accepted the outcome. In addition to affectionate relationships, there was positive behavior shown by <<Disclosure of the infection at the company to gain the support of superiors and colleagues in the workplace>> and <<Disclosure of the infection to friends to confirm the way of socializing in the future>>. Whether or not infection was disclosed, a "give it a try" attitude was characteristic of the general behavior of many participants, for example, <Ask for help myself>.

*I learned a lot by asking the doctor at the hospital. "...This medicine works this way so the virus reacts this way and is deactivated." I am given explanations like that so I thoroughly understand. (#39, male, score: 50)*

The category [Do not be discouraged by uncertainties and difficulties] reflected the tendency of participants in the high SOC group to meet challenges even if they had initially failed. One participant disclosed his infection to a person he had become fond of, which ended the relationship. He also disclosed the infection to the next person he came to love, feeling a moral obligation to tell the other party because of the infection risk. Despite the fact that a relationship ending is hurtful, the participant maintained his stance about disclosing infection.

*Being rejected by the person you want to go out with... I remember three times. Interviewer: "Three times? Did you have any fears about being rejected again (if you disclose the infection)?" Well, it would be a lie if I said no. Interviewer: "After being turned down by several people, don't you feel that you don't want to disclose your infection anymore? Because the person before rejected you, do you think the next person must do the same?" I don't think so. In fact, some people didn't reject me. I don't think that everyone is the same. There are many different people living in this world. (#10, male, score: 56)*

Participants held similar attitudes regarding work. In cases where a participant decided their infection should be disclosed at work, their behavior was to disclose the infection. Even if one company did not hire them, they tried talking to another company about the infection.

### 3.2.3. High SOC group attitudes as a result of coping

Experiences in the category [Being infected cannot be helped and I am prepared for the worst] differed between the high and low SOC groups. Participants in the low SOC group experienced becoming infected with HIV as “the result of giving in to the demand of the other party (sexual contact without using a condom)” or “due to betrayal by a person I trusted.” In contrast, those in the high SOC group felt that “It was my own fault,” <<I accept responsibility for becoming HIV-infected (infection between homosexuals)>>, and <<I am not going to be at the mercy of anger due to the infection (harmful effects of medicines, heterosexual)>>.

*Probably he did not know he was infected with HIV, that he did not pass on the infection with any feelings of malice, and that passing on the infection was not intentional. (#26, female, score: 53)*

The category [Ready to fully live one’s own life] encompassed subcategories that described participants’ motivation to <<Live while regretting one’s behavior that led to infection (homosexual infection)>>, <<I will go straight>>, and to <<Be thoroughly prepared for the onset of AIDS and dying before others>>. Some participants reported that this mental state was not reached immediately after discovering the infection, and was not easy. At the time the infection was discovered, some participants became depressed and desperate. However, having people around them providing support allowed them to organize things in their minds and behave in ways to help discover how to live their life.

*What happened has happened and there is nothing I can do about it. I can’t hide from reality. So, go back to point zero and think about how I want to live my life, that’s what I’ve done. Speaking from experience, having done my best including trying to be mentally positive, I think in the end it’s best to live my life honestly and properly. (#34, male, score: 44)*

## 4. Discussion

### 4.1. Difficulties experienced by people with HIV

Previous studies have shown that major barriers for people infected with HIV in remaining motivated about re-employment are anxiety about their health, education and skills, and workplace discrimination [23, 24]. Although the present study largely focused on those who were already working, there are a range of difficulties faced by people with HIV in terms of their physical and social condition and self-concept. The experience of having been [Cut off from society because of the name of the illness] was only found in the low SOC group. This suggests they had experienced direct (enacted) stigma, such as <<Being told that my disability was not normal>> or <<Being told that you do not get that disease if you live a normal life>>. Most participants felt that although stigma from the community was unfair, they could not do anything about it and had to accept it. A previous study [25] found that enacted stigma and

vicarious stigma (where a person hears of another's experience) were significantly associated with depression and self-stigma. These experiences are likely to damage a person's SOC and prevent its restoration. This was true for the low SOC group in the present study. A study focused on mental illness by Lundberg et al. is the only research to date that has examined the relationship between SOC and stigma [26]. The present study is the first to examine the relationship between the SOC of people with HIV and their experiences of stigma.

Lundberg et al. [26] found the experience of having been socially rejected was significantly associated with low SOC. This association was stronger ( $\beta = -0.357, p < 0.001$ ) than for empowerment ( $p < 0.02$ ) or self-esteem ( $p < 0.01$ ). The results of their research, and those of the present study, confirm the close relationship between SOC and stigma. This is a significant finding; however, the ways in which experiences of stigma impact on SOC have not yet been sufficiently investigated.

The present study found that people with HIV experienced direct stigma in medical settings and in the workplace. In particular, two participants who reported experiencing stigma at work were employed under the Disability Act. This suggests that experiencing stigma in medical facilities and workplaces, where a higher level of understanding is usually expected, may result in an unmanageable and incomprehensible situation that causes confusion and a sense of powerlessness. If people working under the Disability Act experience stigma at work, they have lost a place to feel safe, which may result in despair. Furthermore, unlike vicarious stigma, enacted stigma is inescapable, and may result in beliefs such as HIV infection being the reason for stigma. Therefore, stigma may negatively affect SOC, and this may explain why a person decides not to reveal their illness at work or in other situations.

## 4.2. Coping by people with HIV

Coping strategies of participants with high SOC in the present study were classified as coping with the environments they encountered and cognitive coping. The findings showed that encounters with favorable environments maintained or improved SOC. However, in those who did not report good encounters with people or favorable environments, their high SOC was attributed to cognitive and behavioral coping. Cognitive coping referred to how encountered environments were perceived. Behavioral coping referred to how they changed their own environment. High SOC is considered to make cognitive and behavioral coping possible.

### 4.2.1. *The surrounding environment*

Categories extracted relating to the surrounding environment represented experiences of favorable working conditions and workplace cultures, as well as positive human relationships. Previous theoretical [13] and qualitative studies have indicated that there is a significant relationship between working environment and SOC [27]. SOC reflects one's trust toward one's life and the wider context (surrounding people and environment). In SOC theory, "legitimate others" are those who provide this sense of being trusted, loved, watched, and recognized. Legitimate others bring a sense of security and the feeling that one is not alone. They also give people meaning in life, energy, and courage [13].



### 4.3. High SOC coping strategies

A coping strategy in participants with high SOC concerned the challenge of how they should behave in a situation they could not control (e.g., strong stigma against HIV, a workplace culture that did not allow diversity, difficult work conditions, unstable physical condition, and relationship breakup). These are situations that participants could not do anything about by themselves. Participants in the high SOC group reported trying their best to cope with these stressors.

According to Antonovsky [13], people with high SOC tend to view the world as consistent. An effective way of holding this perspective is flexibly controlling the boundaries of important areas in life. For example, to avoid distress, they might bring part of their lives to a peripheral area that was not as important to them. Participants with high SOC in the present study tried to actively change the boundaries between what was important to them and reality, including compromising on job content and conditions, depending on their own physical condition and environment, and changing the goals of their work or life. They coped with events that had become incomprehensible and unmanageable by bringing them to areas that were less important to them. Kraaij found that people with HIV who were capable of making goal adjustment in their lives were able to maintain positive mental health [28]. The present study confirmed the importance of flexibly adjusting goals.

The group with high SOC escaped from the chaos of their reality by neutrally perceiving the events relating to their infection and by calmly and objectively observing their reality. Antonovsky [13] stated that people with high SOC are not trapped by their emotions too long; instead, they define the nature and dimension of their problems, deal with them, and explore ways to move from chaos to order. The present study found the high SOC group used behavioral coping strategies, deciding to do something about it, taking action, and not allowing themselves to be defeated by a sense of uncertainty or difficulties. Antonovsky [13] regarded participation in consequences as an important element of meaningfulness. Participation in consequences encompasses factors such as autonomy and participation in decision-making; for example, accepting current challenges, taking responsibility, and making decisions as to what to do or not to do. The accumulation of these experiences nurtures a sense of meaningfulness. In the present study, many participants in the low SOC group had given up on having an intimate relationship. In contrast, those in the high SOC group took action and tried not to be defeated by uncertainty or difficulties. Even if the consequence of their action did not turn out as expected, this group considered their judgment to be meaningful because their will and behavior had been reflected in the consequences.

Participants in the high SOC group who were infected through sexual contact tried to accept their responsibility for the infection. In contrast, those in the low SOC group were not able to overcome their sense of being victimized. Antonovsky [13] suggests that many stressors cause problems of blame where responsibility is attributed to others. Those with low SOC tend to blame other people or factors for their problems. In the present study, some participants with high SOC reported experiencing confusion and depression when they learned about their infection or progression to AIDS, despairing and not caring anymore about what they did. However, they reported being able to find ways to cognitively and emotionally

cope with their problems, taking responsibility for their infection, placing the infection within an area of life they could control, and viewing their problems objectively. These participants coped with the difficulties of HIV infection by feeling that they were participating in the consequences.

#### **4.4. Suggestions for practice**

Although it is not surprising that only those with low SOC reported experiencing direct stigma, it is a reality that should not be ignored. Direct stigma has a serious, negative impact on people with HIV. In the present study, direct stigma was reported by people who were working under the framework of the Disability Act. Even if an employer or a human resources manager has knowledge about HIV infection, other colleagues may not share the same level of understanding. HIV infection is an invisible disability, and those employed under the Disability Act tend to be regarded by others with suspicion. Some participants in the present study reported that they did not know what to say when asked by fellow workers what disease they had. Educating employers, human resource managers, and other staff about HIV through corporate training is urgently needed.

In addition, from an industrial health perspective, it may be necessary to develop workplace cultures in which people with health conditions can work and receive treatment without distress. A workplace in which workers with HIV can feel comfortable will be a good workplace for all employees. Everyone risks losing their health at some point. Therefore, it is important to improve working conditions so employees can work according to their health conditions and lifestyles. However, it is also important that good relationships are developed with managers and colleagues through regular communication, allowing people with HIV to gain trust, and be seen as a reliable working member of society. The present analysis showed that participants' social skills were an important factor for SOC, and although changes are needed in the workplace, people with HIV also need to make their own efforts to fulfill the role of a worker.

The attitudes of those with high SOC make them more likely to cope successfully. This provides important clues for future interventions and education. Although international studies have accumulated a wide knowledge base about interventions for HIV infection [29, 30], there have been few studies in Japan. It is important to increase coping skills to support people with HIV, including suggesting alternative ways of thinking about their situation. Unconditional support from families and significant others is important.

#### **4.5. Limitations**

First, no participants in the high SOC group reported experiencing direct stigma. However, this may not mean that they never experienced direct stigma. They may have had experiences they did not report or did not recognize as stigma. Future studies should examine whether or not participants had real experience of stigma, quantitatively clarify how the impact of stigma was recognized, and examine the association between stigma and SOC.

Second, participants in the present study might have been patients in particularly good physical and mental condition. Participants were selected by the nurses working in the specialized

medical facilities, and limited to those considered by the nurses to be in a good enough condition to be interviewed. It may be that recruited participants were those who had good relationships with the nurses and who were considered easy to communicate with. The facilities advised that 5–10 patients declined to participate because they came for treatment during working hours and did not have time for an interview or did not feel well. Some of those who were not asked to participate may not have been physically or mentally well, or may not have had a good relationship with their medical professionals. The present study stopped recruiting participants after 40 interviews, as this was deemed the saturation level. However, it is possible that if those who declined had been included, other categories of experiences might have been extracted. Therefore, the interpretation of the present results requires some caution.

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