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ABSTRACT

Objective To describe the suffering experienced by patients with hypertension, not only regarding symptoms, but also suffering in a social context.

Design A qualitative analysis of semi-structured interview data. Interviews were audio-recorded and transcribed verbatim. A descriptive approach was taken by exploring patient accounts and presenting their experiences and perspectives.

Setting Cardiology clinic in a university hospital (Samsung Medical Center, Seoul, Republic of Korea).

Participants Patients with hypertension and without serious comorbidities who had been followed-up at a cardiology clinic of a training university hospital.

Results Nineteen men and women (male:female=12:7) were interviewed. The mean age was 44 years, and the average hypertension duration was 4 years. All 19 patients reported symptoms allegedly to be associated with hypertension. Anxiety about blood pressure fluctuation and hypertension complications, dislike of antihypertensive medication and associated labelling effect, family stress and refusal to be enrolled in life insurance were commonly found among patients' interviews. Relatively younger (<50 years of age), actively working patients experienced stigmatisation and discrimination in the workplace.

Conclusion The illness experience of patients with hypertension consists of suffering associated with threatened or damaged self-identity at the individual and social level. Medical professionals should have more awareness of the suffering of these patients to improve the quality of care. An education programme with proper focus on the elements of patients' suffering may help to alleviate it.

INTRODUCTION

Hypertension is a very common condition with major public health implications. Although hypertension is not usually associated with 'suffering', because of its asymptomatic nature, qualitative studies have shown that the subjective experiences of patients with hypertension are quite different from hypertension as a biomedically defined

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is a qualitative study on the subjective and individual illness experience of patients with hypertension, which is very difficult to grasp by quantitative tools such as questionnaires and statistical analysis.
- ⇒ The study finding shows a different aspect of hypertension which has usually not been considered to be a disease associated with suffering.
- ⇒ It describes the nature of suffering of patients from their own perspectives, offering a starting point for better education to improve the quality of care.
- ⇒ This study should be considered as hypothesis-generating rather than confirmation of a hypothesis, because of the inherent nature of the study addressing subjective experiences of patients.
- ⇒ Generalisation of the study finding to other settings may be limited.

disease, and the participants of these studies commonly described various symptoms associated with the diagnosis of hypertension.¹⁻⁴ In sharp contrast, most biomedical practitioners maintain a distance from these lay sources of knowledge, insisting on the asymptomatic nature of hypertension and often ignoring the 'subjective' knowledge of the patients.^{3 5 6} In a cross-sectional study, patients with diagnosed hypertension presented with poorer health-related quality of life, while a similar deterioration of subjective state of health was not observed in patients who had not yet been diagnosed but actually had high blood pressure (BP), indicating a 'labeling effect'.⁷ According to the findings of these qualitative studies, hypertension may be considered as a chronic disease with significant suffering that is similar to (or may be in a lesser degree than) other cardiovascular diseases such as heart failure.^{8 9}

While there have been many qualitative studies of patient perspective on hypertension,

the associated suffering has rarely been addressed. The main focus of these studies was how to reconcile the discrepancy between the lay beliefs and biomedical perspective in search of practical solutions for improving adherence to antihypertensive treatment.^{10–12 12 13} Experiences of patients with hypertension have rarely been analysed with the specific aim to reveal patient's suffering.

Though there is little consistency in how suffering is defined, a conceptual framework by Anderson¹⁴ was adopted, wherein it was defined as 'distress resulting from threat or damage to one's body or self-identity', and it is categorised at the individual (physical and mental) and social levels.¹⁵ Even though 'suffering' has a strong connotation of physical pain or traumatic experiences, but a wider framework including physical symptoms, negative emotions and even social distress is suitable for the purpose of this study, which tries to view hypertension from broader and multifaceted aspects, especially the social dimension uninvestigated previously.

While HIV-positive patients can be stably controlled and asymptomatic by effective antiretroviral therapy, it is well-known that they have significant social suffering from stigmatisation.¹⁶ Though hypertension has never been viewed as a disease associated with stigmatisation, it remains to be seen considering that patients cannot be assumed to be free of suffering just because their diseases are asymptomatic and controllable, as in the case with HIV disease.^{17 18} A recent survey reported that patients with hypertension's social activity was significantly affected by the symptoms or medication side effects and suggested that symptoms and concern about complications can have unfavourable influence on not only the mental, but also the social domain of quality of life.¹⁹ However, it was uncertain what kind of social activity was affected in this study because the information of questionnaire was not adequately provided. Further qualitative study is warranted to specify the social dimension of patients' illness experiences.

Suffering is likely to be culture-dependent²⁰ and study findings from a group or country may not apply to another group or country. This study can be seen as hypothesis-generating which necessitates further similar study in different cultural backgrounds.

Hypertension has been associated in previous studies with mental health problems especially anxiety disorder or state anxiety.^{17 18} However, these studies mainly addressed the influence of anxiety on BP fluctuation or white coat effect and the main study finding is that 'hypertension is associated with other (mental health) problem', which seems to be entirely from a health professional's viewpoint. To describe the illness experience from patients' perspectives, the frame of 'suffering', which is inherently subjective, seems to be more appropriate rather than the mental health frame.

The objective of this study is to reveal individual and social dimensions of suffering experienced by patients with hypertension.

METHODS

Study design and participants

This is a qualitative analysis of data collected by semi-structured interview. Participants were patients with hypertension who had been followed at a cardiology clinic of a training university hospital (Samsung Medical Center, Seoul, Republic of Korea) by a cardiologist who is the first author (JS) of this manuscript.

Inclusion criteria were:

1. Diagnosis of hypertension (on BP-lowering medications or documented as having hypertension in their medical record).
2. Consent to participate in the interview.

Patients with serious comorbidities that can confound their hypertension illness experience were excluded.

Exclusion criteria were:

1. History of other cardiovascular diseases, such as heart failure or symptomatic coronary artery disease.
2. History of stroke with neurological sequelae.
3. Chronic kidney disease on dialysis.
4. History of cancer.
5. Other comorbidities causing significant functional or cognitive deterioration and/or difficulty with interviewing.

Recruitment was performed purposively to include a variety of age groups and genders and continued until data saturation was reached. Written informed consent was obtained from each patient before beginning of the interview. No patient refused the interview.

Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

Data collection

Interviews were administered to each participant by one of the authors (JS), face-to-face in the clinic room where patients usually met with their physicians. Participants were interviewed only once. [Table 1](#) shows the list of main and probing questions. Because the interviewer was the patients' treating physician, it may have biased the response especially the experience with physicians and hospitals. All the questions were asked only for past events and not ones in the current hospital. Interviews were audio-recorded and transcribed verbatim and its times ranged from 18 to 43 min. Transcripts were not returned to the participants.

Data analysis

We took a descriptive approach by exploring patients' own accounts and presented their experiences and perspectives. Interview transcripts were reviewed several times and coded by the first author (JS) with a focus on changes in the patient's life due to various aspects of hypertension such as symptoms, diagnosis, interaction with physicians and medications. All the authors reviewed and categorised the codes thematically (physical, emotional and

Table 1 The list of main and probing questions

No.	Main questions	Probing questions
1	When and how did you recognise your high BP?	
2	What was your response to recognising your high BP?	What was the recommendation or measure taken by doctor(s)?
3	What do you think is the reason for your high BP?	
4	How serious is your hypertension?	Why do you think that?
5	Do you have any symptom of hypertension?	
6	What changes have occurred in your life because of hypertension?	Have you experienced any changes in your work, job performance or relationships with your colleagues? Have you changed your life plan? Did you give up any of your wish-list items or hobbies? Did you experience discrimination; eg, enrolling in insurance policies? Any change in family relationships? Any change in sexual activity?
7	Did you receive any advice or education about hypertension?	What were the contents?
8	Are you aware of the complications associated with hypertension?	Are you anxious about this?
9	Have you done any self-monitoring of your BP?	What do you think about it?
10	How do you feel about BP-lowering medications?	If you have reluctance or repulsion for them, why?
11	How was your personal experience with BP-lowering medication(s)?	Did you have any side effects? What measures were taken to reduce the side effect(s) by you and/or doctor(s)? What were the positive aspects of taking BP-lowering medication(s)?
12	Do you have any discontent for the doctor(s) you saw for your hypertension?	

BP, blood pressure.

social) and according to level of suffering. Themes were not predefined but derived from the data in the course of coding, resulting in six themes: (1) symptoms, (2) anxiety for BP fluctuation, (3) anxiety over complications, (4) anxiety/dislike for medications, (5) family stress and (6) stigmatisation/discrimination. Coding and thematic categorisation were performed with Atlas.ti V.9.1.6.0 Windows (ATLAS.ti Scientific Software Development GmbH, Germany). We could not have feedback on the findings from the participants.

To verify analysis results, the authors' disciplinary and theoretical backgrounds are briefly described: The first author (JS) is a male clinician with training as a cardiologist, who is currently working as a preventive cardiologist and a hypertension and dyslipidaemia specialist and also has a Master's degree in public health. The second author (YP) is a female anthropologist with expertise in qualitative analysis, including interviewing and ethnography, especially in the field of medical anthropology.

Interview quotations were selected to illustrate and justify the study findings.²¹ Quoted data were translated from Korean to English by JS, reviewed by YP and edited

by professional English editing service. Patients were identified by participant numbers in the [table 2](#), but gender and age range were used in the quotes for stricter anonymisation. Brackets were used to indicate explanatory comments added by the authors for better understanding, and ellipses to indicate omitted text.

RESULTS

Subject profiles

Nineteen patients with hypertension participated in the study. Their demographic profiles are presented in [table 2](#). Seven female and 12 male patients were interviewed, the mean age was 44 years and the average duration of hypertension was 4 years. Four patients were recently diagnosed with hypertension within a year in the clinic where the study was done. Most of the participants (except two) were either college graduates or were in college at the time of study. All female participants considered themselves housewives. All patients were in the stable maintenance antihypertensive regimen for at

Table 2 Demographic profile of participants

Patient no.	Age range	Gender	Duration of hypertension (years)	Marriage	Education	Occupation
1	60–69	F	10	Yes	High school	Housewife
2	40–49	F	4	Yes	College	Housewife
3	50–59	F	3	Yes	College	Housewife
4	50–59	M	6	Yes	College	Renting (self-employed)
5	30–39	M	<1	Yes	College	Marketer
6	30–39	M	4	Yes	Postgraduate	Architect
7	50–59	F	11	Yes	College	Housewife
8	50–59	F	10	Yes	High school	Housewife
9	40–49	F	10	Yes	College	Housewife
10	40–49	M	1	Yes	High school	Electronics manufacturing, employed worker
11	50–59	F	2	Yes	Postgraduate	Housewife
12	40–49	M	4	Yes	Postgraduate	Marketer
13	50–59	M	1	Yes	College	Teacher
14	20–29	M	8	No	College	Postgraduate student
15	40–49	M	1	Yes	College	Foreign trade (self-employed)
16	30–39	M	7	No	College	Electronics, employed worker
17	40–49	M	<1	Yes	College	Self-employed
18	20–29	M	<1	No	High school	College student
19	30–39	M	<1	Yes	College	Employed worker

least 3 months and there was no case of resistant hypertension and/or treatment failure.

Symptoms

All 19 patients reported symptoms, regardless of whether they thought they were caused by hypertension. Most commonly headache or posterior neck discomfort and a variety of other symptoms such as chest pain or discomfort, palpitation, dizziness, facial flushing, nervousness, and fatigue were reported.

These symptoms sometimes resulted in recognition of high BP for the first time.

[I] had headaches all along. It was so, so bad but I just took some headache pills. One day it was really so bad that I measured my blood pressure. (F/60–69)

Symptoms were reported to occur at various severity levels but usually became a source of significant suffering because of the anxiety they aroused, regardless of the nature or cause of the symptoms or their relationship to hypertension:

Public presentations had not made me so tense when I was a graduate student, but I have become very nervous giving presentations recently. My heart was beating hard after I finished. I thought something could

happen, and that I have to get a heart exam for it. (M/30–39)

Anxiety for BP fluctuation

Six patients discussed feeling anxiety associated with BP elevation or fluctuation, while some patients consider it relatively lightly and tried to be 'objective' about it, other patients described their BP rising as a very frightening experience:

(Doctor) ...it states in your medical record that you noticed your blood pressure was 240/140 at a family medicine clinic. I guess you were surprised by the high reading.

(Patient) The doctor was surprised, and I was too.

(Doctor) How did you feel?

(Patient) The end of the world, maybe? (F/50–59)

Anxiety was not necessarily associated with very high BP and can be aroused by even borderline BP.

If BP is somehow within the stable range, I feel safe and good, but, for example, if it's on the borderline, like 130/90, then I feel anxious. I feel like I have to do deep breathing or something. (M/40–49)

One patient was diagnosed with panic disorder and was confused whether ‘it’s panic or blood pressure’.

[My heart] was going to burst or something. The nurse measured my blood pressure and she said, ‘it’s 140/100, blood pressure like this is nothing!’. I said, ‘I feel like I’m going crazy,’ but with some time, like 20 min, I stabilized... I didn’t know whether it was a panic or a blood pressure thing. (M/40–49)

Anxiety over complications

Many patients were aware of the potential complications of hypertension, especially stroke. Patient anxiety seemed to be more focused on morbidities and disability rather than mortality.

It’s better to die, but it seems rare to die after collapsing from high blood pressure... people just become disabled. That’s most terrifying. Kidney failure is also horrible. I haven’t seen that [dialysis] in my family, but my friend’s father has been doing it for 7 years. (M/30–39)

Family history of hypertension or cardiovascular complications was discussed by 12 patients not only as a cause of their hypertension, but also as a concrete source of fear for complications:

After caring for my father for 3 years, this [cost for caring the patient] can really cost a house, I think this thing, stroke, is worse than cancer. I have to feed him and always be near him, it’s a big deal, seriously. Money for it is a problem but not just that. I hope I will never be like that. (M/30–39)

Sometimes this anxiety is inadvertently reinforced by a physician’s comment, which the patient can feel as almost a threat.

[The doctor] said that ‘you will be doomed when you collapse, and then you will have a stroke’ (F/40–49)

Such a threatening remark came not only from someone who was a physician but also a family member, and was said to a young patient in his 20s.

(My sister said that) ‘your blood vessels become stiff when you grow old and then you’re done for.’ She threatened me again and again. (M/20–29)

Anxiety/dislike for medications

The majority (15/19) of the patients expressed their dislike for antihypertensive medication. Most of them spoke about the burden of lifelong medication. They had fears of side effects, tried to find any excuses to quit the medication, searched for alternatives and hoped to be on a ‘weak’ drug, however, they felt anxious that skipping the medication can be dangerous.

Once you start on the drug it should be lifelong, as far as I know, and some side effects must follow. So, I tried to avoid that as much as I could, even if my

blood pressure was high, and I thought there might be some other way to manage it. (M/50–59)

I don’t want to be on a ‘strong’ drug. Isn’t my medicine on the fairly weak side? (M/40–49)

If you’re on a blood pressure drug, you have to take it forever, and if you stop it, you will be in real trouble. (F/60–69)

They feel that they are ‘something wrong’ if they must take medication, which can damage the integrity of the self, especially for younger patients.

Taking medicine every morning, what can I say, somehow shrinks my self-esteem. I have to take medicine because I have a problem, that’s the thought I want to avoid but can’t escape. (M/20–29)

Not every patient spoke negatively about pharmacotherapy. A minority of patients seemed to rationalise the antihypertensive medication complying with the medical knowledge rather than expressing dislike of it.

I haven’t paid much attention to stories like ‘[blood pressure] medicine is bad.’ We have good medicines available these days. Taking medicine and controlling blood pressure protects the organs and even my life, that’s what I’m thinking. (F/50–59)

Family stress

Patients had concern for their children, that they might become hypertensive because of heredity.

(Patient) My son takes after me... I am quite concerned about him becoming fat. His constitution takes after me, though he is still young, I think he might have high blood pressure some day in the future.

(Doctor) So [he] haven’t measured blood pressure yet?

(Patient) No... well, it really worries me. (F/50–59)

They also talked about altered family relationships after being diagnosed with hypertension. They feared that they would become a burden to the family but felt that they had become a ‘patient’ already, who had to be cared for and was not a normal-functioning family member.

They worried a lot. When I married, we did not have a blood pressure monitor. My father-in-law bought me one, and my wife became my medicine-taking keeper. She worries a lot [over my health]. (M/30–39)

The relationship with my wife somehow changed... our meals, well, looks like a diet in a hospital or something like that. (M/40–49)

Stigmatisation and discrimination

It was a common experience (12/19) that patients with hypertension were refused to be enrolled in a life insurance policy. In the following vignette, the patient felt that he was being discriminated against and had to resort

to an expedient, irrespective of the accuracy of their knowledge.

I wanted to have cancer insurance after my father was diagnosed with cancer... They produced an audio-recording, and the first question was about blood pressure. I have to tell a lie, otherwise that's it. They even refused counselling.... My cousin was working for an insurance company and he said 'just complete, sign and submit the document, and if you get a telephone call, just say that you don't have hypertension. And go to hospital, do something [for treatment] and be careful so that you won't have a brain haemorrhage or something'. (M/30–39)

Among relatively younger patients working as employees, stigmatisation was a serious issue for their career. They felt that there is a social prejudice against people with hypertension that they are somewhat defective. As a personal defence, they tried to hide their condition from others, especially in the workplace. They even changed jobs when they were revealed to have hypertension and were stigmatised.

If someone is taking blood pressure medications, we have a bias that he is just a sick person and he is, somehow, 'not all right'. (M/30–39)

(Doctor) Do they know that you have hypertension at your workplace?

(Patient) No.

(Doctor) Your colleagues?

(Patient) No one knows

(Doctor) Your boss?

(Patient) No.

(Doctor) Don't you have to give them some excuse when you visit the hospital?

(Patient) Yes, [I usually lie] and report a market survey or something... [having to hide your health condition] it's very disadvantageous [for the career] actually, not just that it is likely to be [but really is disadvantageous]... I heard that many companies try to 'manage' employees with hypertension or some [chronic] diseases, differently from others. (M/40–49)

(Doctor) Would it [having hypertension] be a disadvantage to your career, like promotion?

(Patient) Definitely, yes. Because, you know, you cannot neglect alcohol in a Korean company, though I am not in the marketing department. When I go to *hoesik*, [after-hour gathering often associated with binge drinking] I used to drink a lot but now I cut it by half. It may be conspicuous [to colleagues and boss that I try to avert *hoesik*], and there can be a consequence, because I have to run away [in the middle of *hoesik*] to avoid *iicha*, *samcha* [bar-hopping twice, thrice]. (M/40–49)

One of the executives summoned me and said that they got the results of my health check-up that I had to have a re-exam. He asked why and I said that I had high blood pressure. Then he said 'oh, that's problematic...' and asked whether I was taking medicine. I said 'no'. After the re-exam, I told them that the high blood pressure was 'cured'... I later quit and got a job at a different company. (M/30–39)

Workers commonly keep it a secret that they have hypertension. If anything, it's OK that 'I have fatty liver'. We usually drink a lot and have so many *hoesik* so fatty liver is not so unusual but when you say, 'I have hypertension,' people say 'hey, what if you go wrong [get stroke or something]?' (M/30–39)

DISCUSSION

In this qualitative study, patient interviews revealed suffering from hypertension in various domains not confined to suffering at the individual level such as physical symptoms, and were associated with negative emotions that occurred and were reinforced at various social contexts, from interactions with health professionals and family members to a societal level, like at the workplace.

Consistent with previous studies,^{1–3} participants of this study complained of various symptoms, and patient suffering was associated not only with physical symptoms, but also negative emotions aroused by symptoms, mainly anxiety. Fluctuation or sudden rise of BP and concern for complications were also frequent sources of anxiety. In a biomedical perspective, these symptoms were obviously not caused by hypertension but it was perceived as associated with hypertension and a threat to self-integrity, because they were commonly interpreted as foreboding of serious condition (ie, stroke) and acted as reminders that something was wrong with their bodies.

Suffering at the individual level may be relieved by better education and a supportive environment. However, in practice, physicians might threaten patients by reminding them of possible serious consequences of hypertension. A possible explanation for such a threat is the intention to heighten a patient's awareness regarding the importance of proper BP control and compliance with the physician's prescription. Regardless of intention, such comments inadvertently can be over-interpreted by patients and provide a source of anxiety. The patient (M/40–49) shown in the results who was told that 'you will have stroke' from a physician said that she felt 'anger' not only anxiety at the physician's attitude but could not argue with the physician's authority. More than five of the study participants complained that they did not receive proper educational input from physicians or hospitals.

From a biomedical perspective, antihypertensive pharmacotherapy is the standard treatment for hypertension and is backed by strong evidence of outcome benefits. But many patients expressed dislike for medications.

Reasons for such negative bias are various as seen by patients' comments, that the medication should be life-long, bad thing may happen if discontinued and side effects may occur and so on, but thematically converge to the labelling effect.²² The study participants commonly considered taking medicine as a definite and irrevocable labelling as a real patient dependent on lifelong medications, which means damaged integrity of one's body thus a source of mental suffering. That is why many patients tried to avoid it or to negotiate to be on 'weaker' medicine thus to be allegedly a 'less serious' patient. Considering that such behaviours are very common, biomedical explanations apparently have not been very successful at persuading patients, and perhaps inadequate or inappropriate education is the major problem.

Family relationships were also a source of suffering in some patients. Hypertensive patients frequently suffer from anxiety and guilt that their children might have the same disease or that they fear becoming a burden to the family.

From patient interviews, we revealed sufferings caused by social prejudice regarding hypertension, which cannot be alleviated by an individual approach. Some participants, especially younger ones, experience social suffering in the form of stigmatisation and discrimination at the workplace. South Korea is notorious for its workplace culture of long working hours²³ and after-hour gathering, called *hoesik*, which commonly includes binge drinking.²⁴ People with hypertension may be considered as disqualified for working by colleagues and supervisors because they are not likely to endure long work hours and tough conditions, thus forced to try to hide their weakness (ie, hypertension) from others in the workplace.

In Korean workplace culture, *hoesik* is usually considered as an important part of the job for informal communication, and it is commonly associated with group-enforced binge drinking, though the culture is gradually changing. In this workplace culture, people with hypertension are not allowed to attend the gathering because binge drinking is dangerous for people with 'defective' bodies, and such exclusion is an obstacle to being an 'insider'. Interactions between the workplace culture and social prejudice over hypertension result in alienation of patients with hypertension from their workplace. A patient (M/30–39) specifically mentioned this *hoesik* culture and that avoiding it as well as tough working conditions was the main reason that he changed his career.

Though main and probing questions for the interview did not include questions specifically asking for a solution for alleviating patients' suffering, patients commonly expressed discontent about lack of or inadequate education. At least five patients said that they got no education at all and many others said that the information provided was vague or inadequate. And they felt that doctors just urged them to start medications in haste. Many aspects of the patients suffering at the individual level associated with symptoms, anxiety and labelling effects may

be alleviated by proper education. For social suffering, intervention at social level should be considered, for example, anti-stigmatisation campaign. However, such a campaign does not seem to be feasible because there is little social consensus that hypertension is a stigmatising disease (such as HIV/AIDS). Probably the findings from this study may be a starting point for such social empathy.

Because this study is a qualitative analysis in a small group of patients showing subjective experiences, generalisability is an inherent limitation. This study has shown anecdotal evidences only and its generalisability remains to be seen by further studies. The study setting was confined to a university hospital, the participants were all Koreans and the sampling was not random but purposive. Suffering may be culture dependent and the study finding might not be applicable to different countries. Patients' illness experience may be influenced by patient characteristics but information is inadequate for proper categorisation. For example, we do not have information on the reason for referral to tertiary hospital. At least, the patients with major comorbidities and treatment failure cases were excluded, the heterogeneity of the participants is not likely to be high. And we do not know how many of the study participants could be diagnosed with depression and/or anxiety disorders which could influence patients' subjective experience. Because the interviewer was the treating physician of study participants, it may have biased the response, especially the experience in the medical setting.

In conclusion, in contrast with the biomedical perspective, the illness experience of patients with hypertension consists of suffering associated with threatened or damaged self-identity by physical symptoms, anxiety for potential complications and BP fluctuation, labelling effect closely related to dislike of medicine and stigmatisation and discrimination. Medical professionals should have more awareness of the suffering of these patients to improve the quality of care. An education programme with proper focus on the elements (anxiety associated with symptoms, sequelae, BP fluctuation and so on) of patients' suffering may help to alleviate it, at individual level at least. And if patients can be helped to find a better way to cope with suffering at the individual level, they may have more potential to explore coping strategies for social stigmatisation and discrimination.

Contributors The corresponding author (JS) and the coauthor (YP) contributed to the conception/design of the work, analysis and interpretation of data for the work, drafting and critical revising of the manuscript, final approval of the version to be published and agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The guarantor, an author responsible for the overall content, is JS.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Institutional Review Board of Samsung Medical Center, Seoul, Republic of Korea. Reference no. 2010-03-049. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Data used in the study is an interview transcript of patients with consent to be used for research but not permitted to be available publicly as is.

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