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Imprisoned in the cultural stereotypes of overactive bladder: The influence of disease cultural meanings on patients' sick role adaptation in Hong Kong

Abstract

Background: Diseases often carry cultural meanings and metaphors, and these meanings can influence patients' illness experiences. Patients' behavioral responses are not merely influenced by the disease itself as many past studies noted, but are also under the influence of the social and cultural understandings on a disease.

Objectives: Using the case study of patients who are suffering from overactive bladder (OAB) in Hong Kong, this article investigates how the old cultural stereotypes and the new social understandings of OAB intertwined to influence participants' sick role adaptation and behavioral responses toward the disease.

Method: A qualitative approach using in-depth individual semi-structured interviews was adopted. Thirty patients suffering from OAB were purposively sampled from a patient self-help group for OAB patients.

Results: The cultural stereotypes about OAB – as an “old people” disease, as a hopeless disease without cure, as a sexually-related disease, and as a disease of substance use – had significant impact on the participants' social and illness experiences, leading to their difficulty in adapting into their sick role with the behavioral responses of denial, concealment, resignation, and self-seclusion.

Discussion: Cultural stereotypes of OAB had significant influence on the participants' sick role adaptation, which affected their illness experiences. These cultural stereotypes resulted in their behavioral responses of denial, concealment, resignation, and self-seclusion, and led to

participants' difficulties in coping with their chronic bladder conditions and adapting to their new sick role.

Keywords

Cultural stereotype; sick role adaptation; behavioral response; overactive bladder patients

BACKGROUND

Chronic health conditions often lead to a patient's deteriorating quality of life and poor emotional state (Gravely-Witte et al., 2007; O'Neil et al., 2013). Patients' perceptions can greatly influence their emotional response toward illness (De Graaff et al., 2013; Vathesatogkit et al., 2012; Yilmaz-Aslan et al., 2014). The emotional health of a patient can significantly influence his or her behavioral response towards a disease, and vice versa (Rao, 2009). While positive emotions can enhance patients' ability to adapt, negative emotions can hinder them from coping with the changes brought on by disease (Collins & Reynolds, 2008). Chronically ill patients' poor emotional health often impacts their acceptance of the disease (Kurpas et al., 2013). Helping chronically ill patients to achieve a positive emotional state is therefore vital to enhance their ability to cope with and manage their chronic conditions in a more positive way (Lindsay, 2010).

Patients' emotion is closely correlated with how they perceive themselves with their sicknesses. The perception of sick role affects how patients perceive themselves, and thus their behavioral responses toward their diseases. Sick role theory indicates that people who are sick are subjected to social norms in which they have both the rights and obligations. Although having a sick role allow a patient to be exempted from fulfilling his or her original social duties and responsibilities, this also implies a change in the social role of a patient. These changes can affect a patient's emotional status and thus the ability of coping the conditions. The perception of sick role, as a result, closely interlocks with how well a patient can adapt into and cope with his or her disease.

Although literature suggests that sick persons are often entitled to having the rights associated with their diseases according to the sick role theory, I argue that the cultural

stereotypes of a disease can make patients to experience the opposite. The negative stereotypes attached on a disease can result in poor illness experiences among the patients, making them to suffer from difficulty in adapting into the sick role. Although stigma attaching on diseases is not novel in literature, there is a paucity of research about how the cultural stereotypes of a disease can interlock with patients' difficulty in adapting into the sick role, and thus affecting their behavioral responses toward the disease. This study, therefore, adopted a phenomenological approach to fill the literature gap.

Overactive bladder (OAB) and the patients suffering from it were selected as case study to investigate how the cultural stereotypes of this disease can influence the patients in adapting into the sick role. OAB is a common chronic bladder dysfunction worldwide. In some population-based studies in Europe and in Canada, it was estimated that the overall prevalence of OAB in individuals aged 40 years or above was 16.6% (Milsom et al., 2001) and 13.9% (Herschorn et al., 2008) respectively. In Hong Kong, it was estimated that around 15% of the population experienced OAB symptoms (Oriental Daily, 2009). However, there has been little attention given to this disease and its patients despite of its high prevalence, and even less is known about how the cultural stereotypes of OAB can influence patients' adaptation to this sick role and thus their behavioral and coping responses. In Hong Kong, OAB is even less well known. Therefore, this study was conducted to enrich the literature of OAB.

Diseases often carry cultural meanings and metaphors (Sontag, 2001), and these meanings can influence patients' illness experiences (Kleinman, 1988). Patients' behavioral responses are not merely caused by the disease itself as many past studies noted, but they are also under significant influence of the social and cultural understandings on a disease. As a Chinese community, traditional Chinese cultural values play vital influence on people's belief of diseases

as well as the stereotyping of disease and of patients in Hong Kong. Amongst these values, moral expectation and value on sex and gender play an even more remarkable role in influencing the stereotyping of disease and patients in Hong Kong. Diseases such as cervical cancer, HIV/AIDS, sexually-transmitted diseases, for example, often invite stereotyping in Hong Kong, since suffering from these diseases can imply a patient's violation of the traditional Chinese cultural values. However, OAB presents a new insight in the traditional understanding of disease stereotype, as this disease itself does not show obvious moral judgment that violates the traditional Chinese cultural values. Given to the high prevalence of OAB but with low social awareness, this study aims at investigating the cultural stereotypes of OAB, and how these stereotypes affect patients' adaptation to this sick role, which will facilitate the culturally responsive care delivery to be established for the patients with OAB in the future.

An overview of OAB

Urinary frequency, urgency, and incontinence (Easton, 2010) with the absence of urinary tract infection or other obvious pathology (Haylen et al., 2010) are defined as OAB. The cause of OAB is not well known (Gormley et al., 2012), but risk factors are documented to include obesity, the use of caffeine, and constipation (Gibbs, 2008). Poorly controlled diabetes, poor functional mobility, and chronic pelvic pain can worsen the symptoms. Patients often suffer from the symptoms for a long time before seeking treatment (Gormley et al., 2012). Diagnosis is based on the signs and symptoms suffered by patients, and exclusion of other problems such as urinary tract infections or neurological conditions is required (Gormley et al., 2012). Treatment and management for OAB include lifestyle modifications, behavioral therapy, pharmacotherapy, neuromodulation, botulinum toxin therapy, and surgical interventions (Allahdin & Oo, 2010). OAB patients often require long-term treatment and the illness can seriously affect patients'

physical, psychological, social, and sexual wellbeing (Coyne et al., 2011; Nilsson et al., 2011). In fact, the quality of life of OAB patients is documented to be even poorer than other types of incontinent patients (Duggan, 2011).

METHODS

To understand the cultural stereotypes of OAB as well as the relationship with the sick role adaptation and behavioral responses of the sampled OAB patients, a phenomenological approach with in-depth individual semi-structured interviews were conducted. Thirty people diagnosed with OAB were recruited from a patient self-help group for OAB patients in Hong Kong.

Field site: self-help group for OAB patients

The patient self-help group was established in 2008, and it is formed by a group of patients who are diagnosed with OAB, with the aim of uniting the patients with OAB and their family members. Although no urologist serves to moderate the self-help group, the group has connection with several urologists, whom are the attending urologists for some committee members. The self-help group does not have a routine schedule of meeting for all the members, though the committee members had a formal meeting once a month during the study period. Health talks in relation to OAB and its management were the most common activities organized for the members; and these health talks often served as a social gathering for the members.

As the researcher of this study, I did not have any formal connection with the patient self-help group outside the research project. I knew about this patient self-help group because of my cousin, who is a patient with OAB and an active member of the patient self-help group. As a family member of a patient with OAB, I had the opportunity to participate in some activities that were organized by this patient self-help group, which enabled me to build up rapport with the group.

Ethics Considerations

Ethics approval was obtained from the Committee on the Use of Human and Animal Subjects in Teaching and Research at Hong Kong Baptist University prior to the study.

Reflexivity

The idea of this study is inspired by my cousin, who is a patient with OAB struggling with the symptoms for more than a decade. The illness experience was tough and traumatic for her. She had spent years to receive a confirmed diagnosis of OAB until she met a urologist. However, being diagnosed as a patient of OAB did not give her any psychological relief. Rather, the diagnosis implies that she had to receive a series of treatment: pelvic exercise, behavioral training, fluid intake restriction, as well as medication. However, all these therapies fail to work on her. Frustrated by the symptoms and treatment, she began to blame herself for bringing troubles to her family, and started to develop depression which requires psychiatric intervention. Her difficulty in accepting OAB, which was to be influenced by her perceptions of bladder conditions, made her adaptation in the sick role challenging.

As an anthropologist who have been working in health issues, I notice that the perceptions of a disease is a product of our social and cultural environment. No perception is emerged in random, but our social and cultural environment plays a remarkable role in shaping our perceptions toward diseases, making these perceptions to become a stereotype. These perceptions and stereotypes of diseases come to affect how we perceive a disease, affecting patients of how well they can adapt into their sick role and thus their behavior. If we are going to provide a supportive holistic long term care to patients, we should never overlook the significant social and cultural forces in shaping the perceptions of a disease.

This study was inspired by my earlier research on patients with OAB, covering their illness experiences (Siu, 2014b), shopping behavior for doctors (Siu, 2014a), and doctor-patient communication gap (Siu, 2015a). Also, how the significant others of the patients with OAB – such as the family caregivers (Siu, 2015c) and doctors (Siu, 2015b) – perceived about the disease and the patients is to be influenced by the social and cultural forces. Therefore, this study was conducted to investigate the embedded social and cultural stereotypes of OAB in Hong Kong, aiming at providing a holistic picture in explaining the encounters of the participants and their sick role adaptation.

Data Collection

A qualitative research approach using individual semi-structured interviews was adopted. Thirty participants for the interviews were selected from the patient self-help group by purposive sampling, according to the following inclusion criteria: (1) diagnosed with OAB by a medical practitioner, (2) reported behavioral adjustment after the onset of bladder symptoms, and (3) reported emotional disturbance after the onset of bladder symptoms. Those diagnosed with other kinds of urinary incontinence (including stress incontinence, overflow incontinence, mixed incontinence, structural incontinence, and functional incontinence), and those without a confirmed diagnosis of OAB prior to the sampling period were excluded from this study. Although past studies have documented that 17 interviews are sufficient for achieving data saturation (Francis et al., 2010), this study comprised 30 interviews to attain greater confidence in the data. The participants were interviewed on an individual basis between May and August 2012. All the interviews were conducted by one single researcher to ensure quality and consistency. This reduced the risk of receiving insufficient data and data flaws that might be caused by introducing another interviewer. All the interviews were conducted in Cantonese

Chinese, which is the mother tongue of the participants and the researcher, to facilitate the participants in communicating freely without language barrier.

An interview question guide was developed prior to the interviews. This ensured the interview discussion to be stayed on focused research topics. The interview question guide was developed with the reference of the past literature about OAB, the stereotyping, stigma and self-stigma of disease, as well as the data based on the researcher's earlier studies on patients with OAB. The questions aimed at investigating the meanings of OAB to the participants, the participants' experiences with OAB and treatment, the condition of their emotional health, and their coping and behavioral responses toward OAB. The questions were open-ended to ensure the participants having a high degree of flexibility to express their views, feelings, and experiences (Bernard, 2002).

The interviews were conducted in a private room at Hong Kong Baptist University to protect participants' privacy. Because of their bladder conditions, the interviews were paused at the participants' request, and the interview room was located next to washroom. Each interview lasted from 1.75 to 2 hours, and was audio-recorded with their consent. To compensate them for their time, each participant was given a supermarket cash coupon of HK\$100 upon the completion of the interviews.

Data Analysis

Quick data analysis was conducted during the interviews to determine what was known and what needed to be explored further (Green & Thorogood, 2004). A student assistant in social science discipline transcribed the interviews verbatim, and the researcher subsequently translated the interview transcripts into English. Backtranslation was performed by another bilingual student assistant to ensure the translated interviews did not distort the original meaning of the

participants. The process of retranslation was conducted by the researcher when the backtranslated interview scripts showed discrepancies from the original meaning of the participants, and re-backtranslation was conducted to affirm the original meaning of the participants was not distorted.

A phenomenological approach was adopted to analyze the interview data and to discover the patterns and structures of phenomena that are the lived experiences of the participants (Parse, 2001). Using a phenomenological approach, this study examined the lived experiences of the participants in encountering OAB, in interpreting OAB, in coping with the changes associated with the disease, and in stereotyping themselves. A procedure involving intuiting, analyzing, and describing was conducted (Parse, 2001). By learning the self-stereotyping experiences of the participants, and by examining the structure of the participants' experiences, the manifestations of the phenomenon associated with OAB as a meaning of the experiences with Hong Kong's sociocultural structures were recognized and affirmed in the analytical process (Parse, 2001). The meaning and stereotypes of OAB as experienced by the participants was thus determined.

Interview transcriptions were segmented into meaning units, collapsed into categories, and eventually themes through the process of abstraction and constant comparison. Coding tables were developed (Liamputtong & Ezzy, 2005) according to the inductive coding process by allowing the discovery of patterns of behaviors and thoughts (Bernard, 2002). Repetitive codes and themes were noted and highlighted, and new thematic codes that emerged from the data were added to the coding list. A table which identified themes, categories, and codes with supporting interview quotes was constructed. A codebook was kept to record special data. The analytic procedures, codings, and findings were documented in the codebook to assure consistency and accuracy of the data collected. Because the data collection and analysis of this study was

conducted by a single researcher, a recoding process was conducted one month after the first coding as cross-analysis in order to reaffirm the codes and to eliminate possible subjectivity and bias, and to enhance the validity and reliability of the coded data.

RESULTS

Participants

All 30 participants in this study were members of an OAB patient self-help group in Hong Kong, and consisted of 19 females and 11 males between the ages of 32 and 58. They worked in a variety of sectors, including civil service, administration and executive sector, commerce, finance, education, social service, catering, and information technology.

The length of time since diagnosis ranged from 1 to 6 years at the time of the study, though participants had been suffering from the symptoms of urinary frequency, urgency, and incontinence between 5 and 11 years. None of the participants received their diagnosis directly after the emergence of symptoms; they commonly suffered the symptoms for at least two years before they were diagnosed with OAB, and some as long as five years. All the participants required follow-up treatment at urology specialty clinics in public hospitals, although two of them had chosen to terminate this follow-up treatment by the time of the study. Emotional symptoms including insomnia, depression, anxiety, lack of appetite, and lack of motivation were common for the participants after the onset of bladder symptoms.

Informant code	Gender	Age	Occupation	Education level	Years of suffering from symptoms / Years of diagnosis	Follow-up

P1	F	58	Civil servant	Matriculation	11 / 4	Yes
P2	F	50	Secretary	Secondary	9 / 3	Yes
P3	F	45	Executive officer	Post- secondary	4 / 1	Yes
P4	F	35	Web designer	Post- secondary	4 / 1	Yes
P5	F	32	Executive assistant	University	5 / 3	Yes
P6	F	39	Customer relation officer	University	4 / 2	Yes
P7	F	44	Teacher	University	5 / 2	Yes
P8	F	53	Teacher	University	7 / 4	Yes
P9	F	46	Shipping clerk	Secondary	10 / 3	No
P10	F	33	Secretary	Post- secondary	5 / 2	Yes
P11	F	56	Catering	Secondary	7 / 2	Yes
P12	F	45	Civil servant	University	8 / 6	Yes
P13	F	46	Clerk	Secondary	9 / 6	No
P14	F	39	IT technician	Post- secondary	5 / 2	Yes
P15	F	33	Catering	Post- secondary	4 / 1	Yes
P16	F	40	Sales representative	Matriculation	5 / 2	Yes
P17	F	35	Insurance	University	8 / 4	No

P18	F	46	Financial manager	University	4 / 2	Yes
P19	F	51	Merchandiser	Secondary	7 / 3	Yes
P20	M	48	Insurance	Secondary	7 / 2	Yes
P21	M	38	Social worker	University	5 / 2	No
P22	M	44	Teacher	University	6 / 2	Yes
P23	M	36	Welfare officer	University	6 / 1	Yes
P24	M	42	Computer engineer	University	5 / 4	Yes
P25	M	43	Finance	University	6 / 4	No
P26	M	50	Civil servant	University	10 / 3	Yes
P27	M	32	Welfare assistant	Post-secondary	3 / 1	Yes
P28	M	41	Sales representative	Matriculation	5 / 2	Yes
P29	M	54	Sales manager	University	7 / 3	Yes
P30	M	48	Marketing manager	University	6 / 2	Yes

Table 1. Socio-demographic characteristics of the participants

The cultural stereotypes of OAB as perceived by the participants

Disease often carries symbolic meanings to patients (Sontag, 2001), and these meanings become embedded as stereotypes, which influence patients' illness, treatment, and social experiences (Kleinman, 1988). In the case of OAB, these symbolic meanings were embedded in the participants' perceptions as stereotypes. On the other hand, the current social situation also

rooted in the new social understandings of OAB, becoming a stereotype of this disease. These stereotypes resulted in participants' self-stigmatization, and greatly influenced how they adapted into their sick roles, and thus their illness and treatment experiences as well as affected their behavioral and coping responses in turn.

OAB as an “old people” disease

All the participants stereotyped OAB as an “old people” disease. The symptom of urinary incontinence in particular led them to correlate the disease with the elderly. Such stereotype was particularly difficult for the participants to adapt into their sick role, as this stereotype contradicted with the ages of the participants. Such stereotype often resulted in their identity crises. As this participant indicated:

This [OAB] should only be suffered by old people. Only old people lose control of their bladder and need diapers. This [OAB] should not be suffered by a young person like me. If others know that I have lost control of my bladder and need sanitary napkins everyday, how will they view me? It is very difficult for me to accept this disease, because it should not be suffered at my age. Only old people should be incontinent. [P5]

The stereotype of bladder disease as an “old people disease” caused particular emotional upset in the younger participants. As a participant shared such adaptation difficulty:

I feel very bad because I can never imagine having a very sensitive bladder [overactive bladder]. Incontinence... Only old people will be incontinent... Every time when I go [to the urology clinic] for follow-up, I feel so embarrassed. Many patients there are the elderly. I can feel that they are staring at me and wondering why there is such a young patient here. [P10]

OAB as a “hopeless” disease

OAB was widely stereotyped as incurable by the participants. The years of suffering from OAB was significant in affecting the participants' hope for a cure; the longer the symptoms and sufferings, the higher tendency for the participants in stereotyping OAB as a "hopeless" disease. More than half of the participants used "hopeless disease" to describe OAB. Other participants even perceived OAB as worse than cancer. Although both OAB and cancer were thought to require lifelong treatment, cancer was often perceived as more curable than OAB:

Suffering from sensitive bladder [overactive bladder], to me, is hopeless, because it is incurable. The disease will follow you for your whole life. Even cancers are treatable nowadays. If there is no relapse [for cancer] after 5 years, then you are recovered. However, there is no hope for sensitive bladder to get cured. Once you suffer from it, you will suffer until you die. No surgery and no medication can treat it. The treatment often is useless, and unable to relieve the symptoms much. [P17]

This perception of OAB was emotionally stressful to the participants. The stereotype of OAB as "hopeless" and "incurable" was strong, with treatment often regarded as "disappointing", "hopeless", and "endless".

The doctor just gives me some medicine. He said every patient responds differently to the medicine, so I need to have patience. However, I have tried several kinds of medicine already, but they just do not work on me. I have also tried pee training [voiding habit training], as well as [pelvic muscle] exercise. However, I am still unable to hold [urine]. All treatment fails to work on me. I have read a lot of information, and all information says that this disease will follow you throughout your life. I often think that this disease is the worst among all chronic diseases; at least other chronic diseases can get improvement if you follow the treatment, but this disease is very difficult to control even if I am on

treatment and take medicine accordingly. There is no hope to get a cure, but the treatment is endless and the outcome is disappointing. [P24]

OAB as a sexually-related disease

OAB was also commonly stereotyped as a disease that are related to sexually-transmitted diseases to more than half of the participants, since urinary symptoms were perceived as one of the key symptoms of sexually-transmitted diseases. Such stereotype was often constructed on how the biomedical doctors perceived the participants. As this participant shared:

It is embarrassing for me to have this disease. When I went to doctors, telling them about my symptoms, they would immediately ask me if I have any sex just before. They would also ask me many questions about my sexual life. I feel bad, because these doctors seem to think that I am a bad and an immoral woman. They mainly focus on sex matters rather than on my bladder discomfort. I am not quite sure, but it seems to me all bladder diseases are due to sex. [P3]

Such stereotype was also constructed on how the general public perceived bladder diseases. As this participant indicated:

Sometimes I would think that this disease has close relationship with sex. Many friends of mine also have the similar thinking. They would think that if a woman is having sex more often, she will have a higher chance in having this disease. I am not sure, but it seems that the situation will get worse really after sex in most times. It is quite embarrassing to talk about this disease, because everyone will immediately think of sex when they hear about bladder problem. [P14]

OAB as a disease of substance abuse

Aside from the above cultural stereotypes that have long been embedded in the participants' perceptions, new social understandings were also constructed by the society that created a unique stereotype about OAB in Hong Kong: OAB was socially constructed to correlate with substance abuse, in particular ketamine abuse, under the institutional force. Urinary frequency, urgency, and incontinence were portrayed as the physical consequences of ketamine use in the public service announcements of the Narcotics Division, Security Bureau of the Hong Kong Government against substance abuse. This portrayal thus socially constructed the correlation between OAB and ketamine use. Given this new stereotype constructed by the government institution, almost all the participants were reluctant to tell their friends and family about their bladder sufferings. Yet without support, the participants' illness experiences were traumatic and lonely:

I do not want others know about my bladder problem, because I am afraid that they will label me as taking "little K" [ketamine]. Many people will think frequent toileting [urinary frequency] and incontinence is the sign of taking "little K." In such an environment, how dare I tell others about my bladder condition? Being a bladder patient is very lonely, because I cannot tell anyone. The only people whom I can share with are the fellow members of the group. [P12]

A correlation between OAB and ketamine abuse was therefore socially constructed as a result of these public service announcements. This stereotype not only prevented these participants from seeking emotional support, but it also hindered them from seeking appropriate medical treatment, since the stereotype also affected health care providers:

I do feel some doctors seem to be suspicious that I am taking "little K" [ketamine]. They asked me many times if I am taking "little K", especially in the initial stage when I saw

these doctors. I often feel bad after having follow-up treatment, because I am always viewed as a potential “little K” user. Sometimes I wonder if I should give up the follow-up treatment so that I do not need to suffer from this bad label anymore. Most people will relate this disease with “little K”. [P21]

This new social stereotype thus constructed the stigmatization and marginalization of patients with OAB symptoms in Hong Kong society, making the participants to be vulnerable to being labeled as ketamine users. In some extreme cases, participants were marginalized and isolated from their social network:

My colleagues and boss feel doubtful with me when they have noticed that I have to hurry to the toilet often. I know they are gossiping if I am taking “little K” [ketamine]. They avoid having lunch with me, and avoid working with me. My boss has warned me several times that going to toilet often will reduce the company’s productivity, and he will fire those who behave against the law. Some friends also wonder if I am taking “little K”, and they avoid contacting me afterwards. Everyone will just think those who have bladder problems are “little K”-users. I feel bad for being labeled and isolated. [P25]

Sick role adaptation and behavioral responses of the participants

The old and new cultural stereotypes of OAB significantly influenced how the participants adapted into the sick role, and thus their behavioral and coping responses, leading to their behaviors of denial, concealment, resignation, and self-seclusion.

Denial

More than half the participants experienced denial as an initial behavioral response. This response was particularly prevalent among younger participants. As bladder disease was commonly stereotyped as an “old people disease” by the participants, they often found it more

difficult to accept their bladder symptoms at their relatively young age. One participant, aged 35, shared how difficult it was for her to accept her chronic bladder condition:

I do not think that I will lose control of my bladder for long time. These symptoms will not last for long; they are just temporary, I think. Long term incontinence will just only happen on the elderly. I am just 35 years old, so I should be able to get recovered. I think I may just have a chronic infection with some very rare bacteria; but just that the bacteria is too rare that the doctors cannot figure it out, so they just roughly diagnosed my bladder is too sensitive. I do not think that incontinence will follow me for the rest of my life. [P4]

Such denial responses influenced how these participants communicated about their symptoms and cooperated with their health care providers. This participant shared:

I am still young so I do not think I will lose control of my bladder forever. The doctor may not be very confident, so he just told me the worst situation. Although the doctor suggested about having bladder training, I think it is not necessary for me since I do not think that this situation [OAB] will last long. After all I am still young, and I should be able to get recovered. I just take medication, and having bladder training is unnecessary I think. I do not believe that things have gone that bad. [P15]

Concealment

Concealment was another common behavioral response for all the participants, as they felt shameful and embarrassed about suffering from an “old people disease”. This participant shared:

No other people know about my bladder problem except my husband. It is very embarrassing to tell others. How will others view me if I am suffering from this “old people disease”? Some friends have asked me why I need to go to toilet so often, and they are puzzled why I have to rush, not walk, to the toilet. I just lied to them that I had too

much water. It is really too embarrassing to tell them about my disease. I feel ashamed of telling others that I am unable to hold urine. [P22]

The participants' concealment was also resulted from the new stereotyping on the OAB symptoms – they worried if they would be misinterpreted as ketamine users. As this participant shared:

I dare not tell anyone about my bladder condition, because I worry if others would label me as a “little-K” [ketamine] user. Once the television advertisement presenting about taking “little-K” can cause one to suffer from frequent toileting [urinary frequency] and incontinence has been out, I then dare not mentioning about my bladder condition to anyone. Such negative label has been deeply rooted in people's mind now. Keeping my situation in secret should allow me to avoid troubles. [P18]

Because of the stereotypes of OAB, self-stigmatization was significant in motivating the participants to conceal their disease as response. One participant said:

If I were the boss, I would not employ those who need to go to toilet often and [suffer from] incontinence as well, because you can never know if they have a habit of taking “little-K” [ketamine]. After all, taking “little-K” is against the law, and I think no employer will want to bear any risk. No one will believe that you are sick for having these symptoms, because most people will think that it is an “old people disease”. Therefore, definitely I will hide my problem in order to avoid trouble. [P26]

Resignation

Due to the stereotype of OAB as a hopeless disease, most participants developed a sense of resignation about their treatment. The longer they suffered from the bladder symptoms, the stronger their sense of resignation was. Furthermore, the limited improvement they experienced

further reinforced the stereotype of OAB as hopeless, making the feelings of resignation prevailed:

I really feel very frustrated and tired from the treatment. I have been taking medicine, receiving [bladder] instillation [therapy], and having bladder training for many years, but I cannot see much improvement in my bladder condition. I cannot see why I still need to keep on with the treatment if the treatment cannot help me. I really want to give up. It is hopeless for me to get recovered. [P13]

All the participants had encountered an arduous journey of assessment before they were diagnosed with OAB; even after the diagnosis, the long treatment without promising efficacy was frustrating, which reinforced the stereotype of OAB as a hopeless disease, leading to a sense of resignation for them. As this participant stated:

When I first experienced from the symptoms, I had been shopping different doctors and had spent many years to get diagnosed. When I got diagnosed, then I started to suffer from the treatment aside of the symptoms. My bladder does not get any better, and the treatment is endless and strenuous. I have lost my hope to get cured. I am tired of the treatment, and maybe I will give up one day. [P9]

Self-seclusion

Almost all the participants responded with self-seclusion. Worrying others' perception on them, the participants avoided participating in social activities. The feeling of being "imprisoned" was commonly mentioned. As this participant shared:

My bladder problem makes me feel imprisoned. I rarely go out unless necessary, because it is not easy to find a toilet outside. Even if I can find a toilet, I may need to wait in a queue, but I cannot wait or I will wet my trousers. I rarely hang out with my friends now, because

I do not know how they will think of me. They will wonder why I am having this “old people disease”. I will bother my friends too if I go to the toilet so often. [P7]

The participants also isolated themselves because of the new social stereotype about the bladder symptoms, for fear of being stigmatized as ketamine users. One participant said:

I dare not meeting with my friends now. They will probably think that I am taking “little K” [ketamine] if they see me going to toilet often or wetting my trousers. They will not believe that I am sick even if I tell them I am having bladder disease, because most people will think bladder disease is an “old people disease”, and this should not happen at my age. I no longer meet with my friends now. I just feel like being imprisoned, and I cannot see when I can be released from the prison. [P2]

DISCUSSION

Being sick often leads to emotional burden for patients. Besides the physical symptoms, the cultural stereotypes of a disease can also influence patients’ illness experiences, and thus their sick role adaptation and their behavioral and coping responses. Diseases often carry symbolic meanings and metaphors (Sontag, 2001), which are closely related to how the people of a society perceives a disease. Therefore, there is always a close relationship between the social-cultural understandings of a disease and patients’ behavioral and coping responses.

My earlier studies demonstrate that the patients with OAB often suffered from unpleasant experiences, which often began at the time when they experienced the symptoms (Siu, 2014b). Their frustration in seeking a confirmed diagnosis as well as the lack of understanding of OAB among primary care doctors motivated their doctor shopping behavior (Siu, 2014a), making the treatment experiences unpleasant. The unpleasant experiences continued and sometimes could be accelerated when the patients were diagnosed with OAB. In some occasions they encountered

difficult communication with their family caregivers (Siu, 2015c), and more often they experienced significant communication gap with their urologists under gender and power differential (Siu, 2015a). As shown by these earlier participants, they often perceived that they were not being respected by their urologists in the sense that they were not treated seriously, were not understood, and were not given the autonomy in the treatment process. Also, they perceived their urologists as lacking empathy to their sufferings. These perceptual barriers affected these participants to communicate effectively with their urologists (Siu, 2015a). On the other hand, this article seeks to explain the communication gap between these participants and their urologists: the cultural stereotypes as perceived by the participants on OAB also made them to self-stereotype themselves, contributing to their difficult encounter in communicating with their urologists and thus more hardship in adapting to the sick role.

As with other diseases, OAB also carries specific cultural meanings and stereotypes in Hong Kong which made the participants' adaptation into the sick role difficult, affecting their illness experiences as well as their behavioral and coping responses. The OAB symptoms, in particular urinary incontinence, were stereotyped as an elderly disease. The limited efficacy of treatment also created the stereotype of OAB as hopeless to get cured. Furthermore, the stereotyping of bladder disease as closely related to immoral sex as well as the substance abuse behavior further socially constructed a correlation between bladder symptoms and anti-social metaphor in Hong Kong context. These social and cultural stereotypes about OAB were embedded in the participants' perceptions, which affected their sick role adaptation as well as their behavioral and coping responses toward OAB.

A culture's metaphors about illnesses play a prominent role in defining the identity of self, us, and others (Helman, 2001). Adapting into a new sick role and suffering from a disease that

was not perceived as appropriate to a patient's age can lead to a patient's identity crisis (Contrada & Ashmore, 1999), which can influence their sick role adaptation. In this study, relatively young participants suffered from a disease that was widely perceived as an incurable affliction of the elderly, and non-users had symptoms of ketamine abuse. This created a contradiction between the sociocultural understandings of the disease and the participants' own identities, causing them difficulty in adapting to their sick role.

Traditional Chinese cultural values played a significant role in constructing the stereotypes of OAB and thus influencing the participants' adaptation to the sick role. OAB was stereotyped as a disease that are correlated with immoral sexual behavior. Such stereotyping controlled how the participants adapted into the sick role. Women participants in particular were under more significant influence of this stereotype, since morality in sex is a long existing traditional Chinese cultural value expected on women in Chinese community. Similar to the suffering of cervical cancer that can invite moral condemnation as immoral and promiscuity in sex, OAB conveyed a similar symbolic meaning to the participants. Not only the participants themselves, but the health care providers of these participants were also under such cultural influence, which further reinforced this stereotype and made the participants' adaptation to the sick role more difficult. OAB, thus, not only conveyed a negative metaphor in the Hong Kong context, but also served as a mechanism to control women under the patriarchal ideology. The violation between the sociocultural understandings of OAB and the participants' actual behavior, thus, made their sick role adaptation more difficult.

Institutional force can also play remarkable influence on disease stereotype construction. Different from overseas literature, OAB in Hong Kong was often correlated with ketamine abuse. Government institution played a remarkable role in such stereotype construction through mass

media and public service announcements. Symptoms of urinary frequency, urgency, and incontinence – which are the symptoms of OAB – are portrayed as the vital signs of ketamine abuse by these public service announcements. As a result, the road of sick role adaptation was made even more traumatic for the participants because of such stereotype construction by government institution, making the participants to become more vulnerable to stigmatization.

As previous literature shows, a patient's emotional health condition can influence his or her psychological responses toward a disease (Rao, 2009). This article further adds that patients' responses can be remarkably associated with the cultural stereotypes of a disease. At the same time, the participants' responses of denial, concealment, resignation, and self-seclusion also reinforced the stereotypes of OAB, resulting in a vicious cycle for the participants.

Suffering from chronic diseases often implies that patients have to adjust themselves into the new sick role (Kleinman, 1988). Sick role is a unique identity attached to a patient (Cockerham, 2009). Patients must adjust their lifestyles, behavior, and social and cultural values in accordance to their health condition to adapt into the new sick role (Ferguson, 2012). As Ferguson (2012) noted, "being sick or having a specific illness directly affects how we view and understand ourselves, how we interact with others, and how we engage with, and act in, the world around us" (p.314). Hence being ill requires patients to respond to and cope with the changes brought on by disease. Different patients adopt different coping strategies; one of these strategies is disregarding, developed as a form of psychological defense to protect the self-concept and reduce emotional discomfort (Busch, 2005). The participants of this study adopted similar strategies of disregarding and denial, to protect themselves from the negative emotions and the unpleasant experiences. However, the participants' denial of their chronic condition also

indicated their difficulty in, or preventing them from, adapting to their sick role. This negatively influenced their emotional state and their positive coping to the sick role.

The denial response also influenced how the participants communicated with their health care providers. Because of their failure in accepting their sick role, the participants had low treatment compliance by not following to some treatment plans. Low treatment compliance could reduce efficacy, which decreased the participants' treatment compliance in turn, making them failing to comply with the treatment plans. Denial also contributed to their suspicion about their doctors' diagnoses. Past research shows that patients' trust in their doctors significantly enhances their subjective feelings about the treatment efficacy and their willingness to engage positively in treatment (Jones et al., 2012). In this study, the participants' sense of denial prevented them from placing trust on their doctors, lowering their sense of efficacy and their willingness to engage positively in treatment. This response not only affected the treatment outcome, but the participants' positive adaptation to the sick role in general.

Doctors and patients work together as a team for effective disease management. The sick person is expected to seek technically competent help from and cooperate with doctors (Cockerham, 2009). In practice, however, the relative social classes of doctors and patients are significant in determining effective (or ineffective) interactions between them (Cockerham, 2009). The medical hegemony in addition to differentials in power and social hierarchy (Hans et al., 1997) often lead to one-way upward to downward communication from the more powerful doctors to the relatively powerless patients. The hierarchical and power differentials between doctors and patients placed most of the treatment decisions in the hands of doctors (Miles, 1991), while the participants were left with little power to express their own opinions about treatment approaches. The power is on the side of doctors, and doctors' domination in the treatment

process often influences patients' expectations and behavior (Miles, 1991). As patients, the sense of passiveness among the participants intensified their difficulty in sick role adaptation.

On the other hand, doctors' values and perceptions are also influenced by a society's values (Miles, 1991). The professional roles of doctors are not socially and culturally neutral. Rather, doctors will categorize patients as "good" or "bad" basing on their own cultural values (Miles, 1991), preventing from treating their patients in an objective and uniform way. Therefore, basing on the new social construction on the correlation between bladder symptoms and ketamine use, the health care providers were to be internalized with this new stereotype, influencing them how they perceived and treated the participants. Under such social and cultural influence, the behaviors and attitudes of these health care providers reinforced the new social stereotype in turn, making the correlation between bladder symptoms and ketamine use as more resilient.

Past literature shows that chronic diseases can lead to a sense of imprisonment among patients (Ebbeskog & Ekman, 2001), and this echoes with the experiences of the participants. The participants were displayed with the sense of imprisonment inside the stereotypes about OAB. The fact that bladder dysfunction was stereotyped as an elderly disease imprisoned the participants in suffering from the identity crises; OAB's perceived incurability left them frustrated with treatment and conveyed to them that they were imprisoned physically with the disease for life; and the socially constructed correlation with immoral sex as well as with ketamine use imprisoned them socially from seeking social acceptance and support. The intertwining of these stereotypes was thus imprisoning the participants physically, socially, and emotionally. These stereotypes led the participants to deny, to conceal, to resign from their illness, and to isolate themselves from their social networks, which further reinforced their sense

of imprisonment as a result. This not only impacted their sick role adaptation, but also reduced their incentive to seek help and treatment, reinforcing their separation from support networks.

Although the traditional understanding of sick role does not put responsibility or blame on patients (Cockerham, 2009), the participants of this study experienced the opposite. Suffering from stigma is common in many patients' illness experiences. It conveys how feelings – both of the afflicted individual and those around them – about the illness negatively affect a patient's self-esteem (Cockerham, 2009). Stigma is closely linked with people's perceptions and cultural stereotypes of a disease (Kleinman, 1988). In this study, the cultural stereotypes about patients with bladder symptoms led the participants to be stigmatized as immoral and as ketamine users. Social stigma evokes significant emotional response in chronically ill patients (Halding et al., 2011; Richard & Engebretson, 2010) and can result in defensive actions (Halding et al., 2011). The social experience of being scorned intensified the participants' behavioral responses of denial, concealment, and self-seclusion, which preventing them from seeking social support. Social support is vital for chronically ill patients' adaptation to their sick role as well as the satisfactory maintenance of their health conditions (Hill et al., 2013). Without it, patients can be hindered from coping with their chronic conditions with positive attitudes and behavioral responses (Halding et al., 2011).

Even though not all the participants experienced tangible stigmatization, they commonly imagined that they would be stigmatized if others noted about their bladder condition. This strongly held belief evoked corresponding behaviors and reactions that ultimately became a “truth” to the participants (Merton, 1968). In this way, stigmatization became a self-fulfilling prophecy through the participants' imagination. The fact that participants perceived this stigmatization so readily not only impacted their positive adaptation to the sick role, but also

reflects the general stereotype and lack of understanding and acceptance about OAB in Hong Kong. As a result, participants denied and concealed their illness, as well as isolating and self-stigmatizing themselves, which further prevented them from seeking proper care and social support, leading to the breakdown of their social networks.

The findings suggest some important implications to enhance future chronic care of the patients with OAB. In Hong Kong, currently there has been little attention and support to this group of patients. Therefore, more attention and care will be needed for them. Also, positive messages in terms of treatment will warrant positive sick role adaptation to these patients. The social and government institutions should be more cautious in avoiding stigmatization of OAB in their future anti-substance abuse campaigns.

CONCLUSION

This article examines the interlocking relationship between the cultural stereotypes of OAB and the sick role adaptation of the patients with OAB in Hong Kong. Because of their chronic symptoms as well as the stereotypes of OAB, the participants in this study suffered from various physical and emotional difficulties, resulting in their behavioral responses of denial, concealment, resignation, and self-seclusion. The participants' illness and social experiences, stemming from the cultural stereotypes of OAB, played a prevalent role in causing these behavioral outcomes. The behavioral responses also indicated that patients experienced significant trouble in adapting to and coping with both the physical realities of their chronic bladder conditions as well as the sick role into which they were placed.

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