

Older Adults' Perception of Chronic Illness Management in South Korea

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Objectives: Despite the recent emphasis on a patient-centered chronic care model, few studies have investigated its use in older adults in South Korea. We explored how older Korean adults perceive and cope with their chronic illness.

Methods: We conducted focus group interviews in Seoul, Korea in January 2010. Focus groups were formed by disease type (hypertension and type 2 diabetes) and gender using purposive sampling. Inclusion criteria were patients aged 60 and over who had been diagnosed with diabetes or hypertension and received care at a community health center for at least six months prior to participation. Interview data were analyzed through descriptive content analysis.

Results: Among personal factors, most participants felt overwhelmed when they received their diagnosis. However, with time and control of their acute symptoms using medication, their worry diminished and participants tended to denying being identified as a patient or sick person. Among socio-familial factors, participants reported experiencing stigma with their chronic illness and feeling it was a symbol of weakness. Instead of modifying their lifestyles, which might interfere with their social relationships, they resorted to only following their medicine regime prescribed by their doctor. Participants also reported feeling that their doctor only prescribed medications and acted in an authoritative and threatening manner to induce and reinforce participants' compliance with treatment.

Conclusions: For successful patient-centered management of chronic illnesses, supportive environments that include family, friends, and healthcare providers should be established.

Key words: Chronic disease, Elders, Perception

INTRODUCTION

In South Korea, 60.5% of older adults aged 65 and over were found to have more than two chronic conditions in 2011 [1].

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The prevalence of hypertension is 59.3% in men and 68.5% in women aged 65 and over the prevalence of diabetes mellitus is reported to be 24.3% among men and 19.3% among women in 2012 [2]. From 2007 to 2011, the prevalence of hypertension continuously increased among those aged 65 and over [3]. The prevalence of these risk factors resulted from uncontrolled blood pressure [4-6]. Moreover, medical expenditures to treat hypertension and diabetes mellitus increased 9.0 fold and 8.0 fold, respectively from 1995 to 2005, thus treating these illnesses became a challenging issue for the Korean health care system [7].

To deliver proper care to people with chronic illness, the World Health Organization proposed the Innovative Care for

Chronic Conditions guidelines [8], which were proposed by Wagner et al. [9] and Wagner et al. [10] as a modified chronic care model. This paradigm emphasized the importance of building positive and integrated strategies for managing chronic illness by creating a team of active individuals, family members, community resources, and proactive health care providers. In this model, identifying the individuals' perception on their own chronic illness is fundamental to the successful management of their illness.

Literature on medical sociology has been emphasizing the importance of cultural and social impacts on patients' perception of their illness. The social construction of the illness perception approach provides a powerful counterpoint to the usual approach that searches for biological causes for changes to health and the development of illness [11,12]. As Conrad and Barker [11] stated, "the meanings of phenomena do not necessarily inhere in the phenomena themselves but develop through interaction in a social context." Despite the increasing burden of chronic illness and the recent emphasis on creating patient-centered chronic care models, few studies in Korea have investigate the perceptions and experiences of patients with chronic illness [13]. The effective management of chronic illness is a complex, socio-cultural process because patients with chronic illness derive their perceptions about the specific contexts of living with a chronic illness from experiences in daily life [14]. Considering this approach, effective management of chronic diseases is achieved by not only understanding patients' individual perception of diseases but also the socio-cultural context of their lives. In this study, we explored the perceptions of older Korean adults with chronic illnesses and the influence of their coping patterns. In addition, the influences of their social and clinical environments were investigated.

METHODS

Sampling

We conducted focus group interviews in January 2010 to identify the Sampling and Procedure perceptions of patients with chronic illness as part of a project to control and prevent cardiovascular diseases in Seoul, which was funded by the Seoul Metropolitan Government [15]. Four focus groups by disease type (hypertension and diabetes) and gender were formed using purposive sampling. Participants were recruited from 25 public health centers in Seoul. The inclusion criteria

were patients aged 60 and over diagnosed with diabetes or hypertension and not experiencing any complications. Moreover, those who had received treatment from the public health center for their chronic illness within the previous six months were eligible for inclusion.

Four trained research assistants visited the public health centers and recruited participants who answered a survey on their general health and chronic illness [16]. At the end of the survey, patients were asked if they were willing to participate in a focus group interview. A total of 35 patients showed interest and were contacted by telephone. People who were not able to meet for a face-to-face interview were excluded. In total, 15 males and 11 females agreed to participate in the group discussion.

First, the groups were separated by gender to provide a comfortable environment for data collection, which is common in studies using focus groups. In addition, we tried to mix participants of different ages (60 to 70 vs. over 70) and with different status of chronic illness management. Participants' status of chronic illness management was classified as adherent or not considering their blood pressure or blood glucose levels and frequency of exercise, alcohol drinking, and smoking according to information provided in the survey questionnaire (Table 1).

Focus group interview questions were generated by literature review and after several discussion sessions among authors. The focus group discussion started with individual introductions, and participants were asked to share their perceptions and general opinions of health and illness as well as the causes of illness, treatment, and control of illness and their ex-

Table 1. Number of participants in each of the four focus groups

	Hypertensive group		Diabetic group		Total
	Male	Female	Male	Female	
Adherent ¹					
60-69 y	2	1	4	1	8
70-79 y	2	1	1	3	7
Non-adherent ¹					
60-69 y	2	3	1	2	8
70-79 y	2	0	1	0	3
Total	8	5	7	6	26

¹Participants were divided into adherent and non-adherent groups according to the status of chronic illness management using blood pressure or blood glucose levels and responses to the frequency of exercise, alcohol drinking, and smoking from the survey questionnaire.

periences with and expectations of health care providers. Interviews were conducted in a room equipped with a videotaping device and one-side mirror. Each interview lasted for approximately one and half hours. A moderator and assistant moderators led the discussion with minimal interventions to avoid interrupting the discussion flow and exchange of ideas among participants.

Coding and Analysis

The institutional review board of Hallym University (HIRB-2009-0004) approved the study. Data including personal information were removed to preserve participant anonymity. Informed consent from participants was obtained in the beginning of each session.

Professional transcribers who observed the interviews transcribed the primary transcriptions. All five researchers participated in the focus group discussions as moderators and wrote reflective notes and memos upon completion of each focus group. After completing each focus group, hour-long debriefing sessions were held.

Interview data were analyzed through content analysis [17] guided by *The coding manual for qualitative researchers* [18]. The four transcripts were first coded by the two researchers who moderated the sessions, and then they were reviewed by the other three researchers. Discrepancies were discussed until an agreement was reached. We began our data analysis by open coding the transcripts to identify intriguing words, phrases, and statements. Each set of transcripts was read separately for key themes, first by gender followed by disease type. The status of each participant's chronic illness management as well as gender and disease type were noted when we analyzed the

script to see whether there were differences across these variables. Emerging codes, categories, and themes were entered in matrices by disease type and gender so that within and between group comparisons could be performed. Finally, we coded and categorized emerging ideas rather than merely describing the topics that were discussed during collection.

Preliminary data were coded for when and how participants were diagnosed, their feelings about being chronically ill, their perceptions of the causes of their chronic illness, management strategies, and perceived barriers in managing their illness due to socio-familial factors and limitations of their healthcare providers. Several common themes emerged from the first stage of 'interpretive' script reading, and other themes became clear after several additional rounds of reading. According to the common themes we discovered, coded data with similar meanings for each theme was then merged and categorized. The initial themes selected included denial, fear of complications, hiding their illness from others, fear of stigmatization, and having to rely on medications with insufficient attention to lifestyle modification. These themes were matched with three domains: personal factors, socio-familial factors, and factors related to healthcare providers. Any disagreements or differences in describing, synthesizing, or explaining the data were resolved in author meetings. Final themes and selected categories were presented in Table 2.

RESULTS

Participants' perspectives toward their chronic illness were categorized into three themes as follows: denial and latent fear (personal domain), hiding their illnesses (socio-familial

Table 2. Participants' perceptions about their chronic illness

Domains	Themes	Categories
Personal	Denial with latent fear	Initial and occasional fear of having uncontrollable complications Feeling relieved after medication use controlled symptoms and thereafter denying they are ill Existence of a constant, latent fear of an unexpected episode with bad consequences
Socio-familial	Hiding their illness to maintain social responsibilities	Wishing not to be identified as a patient due to the fear of being stigmatized as weak or a failure Fear of being isolated at work or by significant others
Health service provider	Lack of attention to lifestyle modifications by healthcare professionals	Lack of significant and consistent attention from healthcare providers Passive self-management by exchanging information with significant others who also have a chronic illness No sense of urgency in needing to change their lifestyles if medicine is taken regularly

domain), and feeling neglected (healthcare provider domain).

Personal Domain: Denial With Latent Fear

Study participants' initial responses to being diagnosed with a chronic illness were reported as shocked and intensively overwhelmed and included fear, anger, sadness, depression, anxiety, apathy, and denial. Participants expressed intensive apprehension about the possibility of sudden death and complications that could come from their illnesses. Some expressed serious concern by saying they felt more fearful about having hypertension or diabetes than they would have been if they were diagnosed with cancer. These worries seemed to originate from difficult stories that they reported hearing from friends, family members, and doctors.

"When I heard that I had hypertension, I was so scared to death with horrible thoughts and images of losing motor skills, having a stroke, or other problems." (female with hypertension)

"My doctor told me that I am like a bomb that can explode at any moment. I was also told that if my blood vessel explodes, I am going to become blind. I need to treat my diabetes right away." (male with diabetes)

Despite the initial intense period of apprehension, most participants' susceptibility to certain complications had been lowered after medication use. However, some participants still experienced occasional fluctuations in blood pressure or blood sugar levels as well as complications such as stroke or syncope due to uncontrolled blood pressure and/or sugar levels.

Nevertheless, most participants seemed to superficially deny that they were in poor health. In addition, most participants seemed to view chronic illnesses as something with no cure that is a permanent part of their lives. Moreover, regardless of their adherence to treatment, some participants expressed feeling that chronic diseases just commonly occur in adults their age.

"I have had diabetes for seven years, but I don't feel much different. I don't feel hungry or get thirsty more often than when I was first diagnosed. Other than changes to my glucose level, I don't feel any differences." (female with diabetes)

"This is not something that will be 'cured.' I know that my disease will go on forever and be with me until I die. It has

been about 15 years now. Most of my body is not perfect, but nothing is that bad. My eyes are the same as before. Although I still feel worried whenever I see pictures or read about diabetes. I feel okay most of the time." (male with diabetes)

Notably, ambivalence was commonly found among participants. While participants superficially expressed confidence in their ability to manage their disease and referred to themselves as a 'healthy person,' they also expressed unavoidable worry about the possible complexities and unfortunate cases that they heard from their friends and family might result. Several participants expressed that they were religiously taking medicine to prevent such events.

"I usually take my medicine habitually. When I forget to take my pills, I find that I do have high blood pressure that day. You can't just wait calmly without doing anything [after you hear someone's bad story]. Now, I take medicine religiously." (male with hypertension)

"Often, I hear about someone with a very severe case of diabetes. Whenever I hear that kind of story, I feel dreadful. I feel like it is going to happen to me, and it [the story] stays on my mind for a while after." (male with diabetes)

"I measure my [blood sugar] level several times a day. My fingertips become black after so many punctures. But, I feel relieved because I can also control my diet according to the levels I read." (male with diabetes)

Socio-familial Domain: Hiding Illness to Maintain Social Relationships

In our study, many participants were displeased by the insufficient amount of social support they received and refrained from telling others that they had a chronic illness. When they were in jobs, participants felt apprehensive about being potentially excluded from promotions in their job and social functions among friends if they told them about their diagnosis. In addition, many felt afraid of being pressured to retire from their jobs due to their chronic illness. They asserted that having a chronic illness carried a stigma as failing to manage oneself properly. Negative self-images, low self-esteem, and blaming oneself were notable, unintended consequences of having a chronic illness among our participants.

"Well, it is kind of embarrassing. ... People would consider

me as a person who is really poor at managing myself. ... People don't trust sick people. Sick people can't even borrow money from others." (female with hypertension)

"I don't tend to talk about my hypertension. [Unless I bring it up first] others see me as a healthy person. So, why should I bring it up? If I say I have hypertension, then I would be considered an old or sick person. It would damage my personal image. I am not trying to hide it, but I just don't talk about it if it is not necessary." (male with hypertension)

Some participants, especially female participants, also said that they did not want to discuss their chronic illness at home. Participants believed that talking about their illness only burdens their children and often harms their relationships.

"If I say I need to control my blood pressure, they [my family] don't like hearing it. They feel burdened, but they can do nothing to help. My children need to work and earn money, so I need to take care of my grandchildren. Nothing can change." (female with hypertension).

In addition, participants voiced their difficulties with following chronic care regimens, such as consuming a low-salt diet and regular exercise. Women participants reported having to prepare meals for all of the family members. However, they could not ask the other family members to also consume a low-salt and high-vegetable diet. Moreover, they said that they could not register for exercise programs because they are during the daytime when they have to take care of their grandchildren.

"My son never wants to eat brown rice, so when I cook rice, I set aside brown rice just for myself. Then, it is okay for both of us." (female with diabetes)

"I can't do my daily exercises. Only after I am done with my house chores in the evenings, I can go out and walk around my neighborhood." (female with hypertension).

Often, male participants expressed difficulties in changing their habits because they also want to maintain their social network. In particular, the food and alcohol-related culture in Korea seems to enforce these perceptions. In Korea, food and alcohol consumed together are considered important customs for maintaining one's social networks. Therefore, changing one's diet and limiting alcohol intake seem to be a major chal-

lenge.

Among female participants, common, simple changes were able to be made that would not interrupt other family members' eating habits or lifestyles. These included having steamed barley or brown rice and performing simple exercises such as walking or bike riding. Occasionally, food supplements that are otherwise not recommended by health professionals were taken as remedies following the recommendations of close friends and family.

Healthcare Provider Domain: Insufficient Attention From Professionals

During participants' visits to health centers, they reported rarely having a chance to discuss or learn about realistic care plans they can implement at home. When they received their diagnosis, most reported that their doctors prescribed medications and recommended they follow the prescription. Most participants also stated that their doctors did not actively discuss chronic illness management strategies such as following an appropriate diet or regular exercise. Some participants reported that their doctors only stated recommendations such as not eating salty foods, exercising, and that their blood pressure should be lowered while they were completing other tasks. Moreover, participants stated that their doctor rarely checked whether their patients actually followed their prescriptions.

Unless acute symptoms or problems arise, most doctors tended to only perform routine tests. Instead of engaging in continuous and regular in-depth conversations with their patients, doctors tend to ask similar questions at every visit as long as patients' test results remain stable. When our participants' blood pressure or blood sugar level was not properly controlled, doctors emphasized the importance of the medication regimen and tended to increase their doses. Most participants said that their doctors did not spend much time with them and showed little concern about reducing medication doses.

"When I go to my doctor, he [or she] just checks my blood pressure and gives me another month-long prescription. That's it. When I want to ask about my blood pressure, I am told it is a little too high. My doctor always seems to be very busy. (At the doctor's office) I wait for about an hour, but can only see my doctor for 2 to 3 minutes. He [or she] never has time to discuss other remedies." (male with diabetes)

As a result, participants seemed to be heavily reliant on medications and considered them the most crucial, convenient, and effective way of managing their chronic illness. However, over reliance on medication use is often used as a reason to not become engaged in other efforts such as necessary behavioral changes. Therefore, behavioral changes tend to not be considered an integral factor that should accompany regular medication use.

"My medicine is a small pill that gives me peace." (male with hypertension)

"It's been about 10 years since I was diagnosed with hypertension. The small 25 mg tablet works amazingly well. I take it religiously. I have no worries now." (male with hypertension)

A number of participants admitted that they felt no urgent need to change their lifestyles because their unhealthy behaviors did not tend to cause a problem as long as they took their medicine regularly.

DISCUSSION

A recent consensus on managing chronic illness has emphasized the importance of patients' self-management and taking leading roles in managing their care [18-20]. To provide better medical services for people with chronic illness, healthcare providers, therefore, need to understand how patients perceive and cope with their illnesses. Our participants recognized that chronic illness carries a stigma in Korean society, which has been similarly reported in other Asian and Western countries [21,22]. Patients in our study made efforts to hide their chronic illness from others and refused to be named as patients with a chronic illness.

These negative perceptions of patients with chronic illness seem to have resulted from unsupportive socio-familial and healthcare environments. First, participants reported not receiving support from their family and friends with whom they discuss other personal issues in their daily lives [13,21,23,24]. Friends and family should help patients to be motivated to manage their chronic illness actively [25]. It is important for someone with a chronic illness to have instrumental support as well as emotional and interpersonal support that helps patients manage their illnesses and maintain daily life. Supportive friends and family members allow patients to share and discuss

personal issues that they experience while managing their illnesses [26]. However, our results showed that Korean patients did not have enough support from their social network. Often, their children had limited knowledge and understanding of the importance of lifestyle modification, which is a critical factor in managing chronic illnesses for older adults.

Second, participants in our study did not receive proactive support from their healthcare providers, and reported not being able to establish productive interactions with their healthcare providers. Experiences of poor communication with healthcare providers and a lack of patient involvement in decision making for chronic illness management have also been reported in previous studies in Korea [13] and Australia [27]. Patients who were failing to manage their chronic illness tended to be less informed, have little interaction with their physician, and be less involved in building a healthy lifestyle, which are all necessary in chronic care management, than were those who successfully managed their chronic illness [28]. Studies have reported that these negative consequences result from the acute care-oriented and fragmented healthcare systems [16,21,22]. In previous studies [28,29], study participants also pointed out that doctors only respond to acute medical problems, rather than being engaged in continuous and regular in-depth conversations with their patients.

Furthermore, meaningful in-depth communication such as individual planning and continuous monitoring of chronic care needs requires collaborative efforts among a diverse range of healthcare professionals [19,30], thus initiation is challenging. For example, when being diagnosed with hypertension or diabetes, participants reported not receiving adequate explanations about how to care for their illnesses or where to find educational resources. Instead, they felt that the warnings they received made them vulnerable to fears and frustrations. Further, even adherent participants were not able to receive timely support, which made them frustrated and withdrawn. Therefore, the evidence-based interventions suggested by the World Health Organization are not being implemented in this healthcare environment [20].

Providing adequate information and support is critical in managing chronic illnesses. Without knowledge and support, patients tend to view their chronic illnesses as a life-long burden with no cure, so they became overwhelmed and discouraged. Their susceptibility to complications then becomes lowered without a hope or trust in the social support and healthcare system [13,27,31,32]. Previous findings reported that pa-

tients who believe they have a low susceptibility to further complications resulted in passive attitudes among patients, and these patients tend to fail to actively manage their chronic illnesses [26]. Therefore, helping patients not become overwhelmed, rather remain confident of their ability to manage their illnesses, should be instilled by a proactive healthcare team.

Paradoxically, participants in our study expressed wanting to hide their illnesses, but they also exhibited a strong wish to control their illnesses. To provide a tailored care plan to those with chronic illness, health care providers and the patient's social network should be motivated, knowledgeable, believe improvement is possible, and possess effective communication skills [27,33]. Mirzaei et al. [28] described the importance of improving accountability between health care providers and patients. National strategies for managing chronic illness should contain more specific and active implementation plans for chronic care.

We expected gender differences in perception and behaviors among our participants when considering the culture of the older Korean adult population and our analysis did indicate that some differences between the gender groups existed. For example, female participants frequently mentioned difficulties in changing their diet and lifestyles due to a lack of family support or time because they take care of their grandchildren. However, male participants expressed difficulties and worried about maintaining their social life that usually includes smoking and drinking alcohol. Nevertheless, major differences in terms of perception and behavioral responses to their illnesses were not found between men and women. Both groups reported having latent fears, did not want to be labeled as a 'patient', and were frustrated with the lack of support from their friends and family and their healthcare providers.

Our study had the following limitations. First, this study was conducted as a part of a large project focusing on chronic care in the public health centers in Seoul, a metropolitan city in South Korea. Therefore, participants were selected from a list of patients available at the public health centers. Most of our participants had the same chronic illness for more than 10 years and had visited various health clinics and hospitals; however, their experiences at local clinics or hospitals did not tend to be particularly different. Nevertheless, experiences reported in this study cannot be generalized to all older adults in Korea. In addition, the severity of each patient's chronic illness was not considered. Future studies with patient samples from different

health sectors that consider the severity of illness are needed.

This study confirmed that challenges exist for managing chronic illness among older adults in Korea. Patients face barriers in self-managing chronic illnesses that include social stigma and a lack of support from socio-familial resources and healthcare teams. Yet, patients still want to manage their chronic illnesses and be socially involved even though it makes disease management difficult. Our findings suggest that urgent changes to the healthcare service should be made to improve care for older adults with chronic illness. One important change would be to create productive interactions between patients and healthcare service providers. Moreover, our study implies that there is an urgent need to develop more active policy efforts for sociocultural and psychological improvements that can reduce patient stigma as well as strengthen social support so that a patient's community can become a supportive network.

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CONFLICT OF INTEREST

The authors have no conflicts of interest with the material presented in this paper.

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