

Patient Perspectives of Chronic Disease Management and Unmet Care Needs in South Korea: A Qualitative Study

Journal of Patient Experience
Volume 10: 1-6
© The Author(s) 2023
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/23743735231213766
journals.sagepub.com/home/jpx



Kyunghee Yi, PhD¹ and Sujin Kim, PhD² 

Abstract

Understanding and incorporating patients' perspectives are necessary to address the emerging challenge of chronic disease management. Our study examined patients' perceptions and experiences for the current chronic disease management system in South Korea. Focus group interviews were conducted on 23 patients and 11 themes emerged by qualitative content analysis. The participants experienced in terms of provider-patient interaction: doctors only prescribe medicine, doctors who provide conventional advice, doctors who do not respect the patients' opinion, long wait times and inadequate consultations, lack of personalized care, and freedom to select another doctor. They also experienced in their community and health system: struggling alone, commercial media and folk remedies, lack of IT technologies for care, demanding visiting services, and lack of collaboration in the community. We found that patients needed comprehensive and personalized care, respect from providers, and self-management support and collaborated care with the community using information technologies advancement. Our findings suggest that a fundamental change in the South Korean healthcare system paradigm is required for successful chronic care, including payment and healthcare delivery systems.

Keywords

patient experience, chronic care, chronic conditions, qualitative research, South Korea

Introduction

The burdens of chronic disease are increasing worldwide. The global share of chronic disease accounted for 60.8% of all deaths in 2000, and increased to 73.6% in 2019 when 7 of the 10 leading causes of death were chronic diseases.¹ In South Korea, chronic diseases caused 79.9% of all deaths in 2019 and accounted for 8 of the 10 leading causes of death.² These diseases challenge the current healthcare system, which is oriented to acute services.³ Since chronic diseases are rarely cured and require continuous, coordinated, comprehensive, and person-centered care, healthcare systems should be redesigned to address the needs and concerns of those with chronic diseases.⁴ The quality of service delivery should take into account patients' experiences and perceptions of their care.^{5,6}

Several frameworks have been proposed for addressing the complex needs of patients with chronic diseases within the healthcare system. One notable example is the Chronic Care Model developed by Wagner, which advocates for collaborative efforts among patients and families, nonphysician personnel, evidence-based proactive providers,

and community-based resources.^{4,7} Similarly, the innovative care for chronic conditions framework suggests that patients and their families, community partners, and health professionals should be motivated to work together.⁸ Another study emphasized the significance of care coordination and integration and the utilization of tools such as population management and information technology, with a specific focus on prevention, self-management, and primary health care.⁹ This chronic care paradigm emphasized the significance of identifying patients' needs, preferences, and perceptions in designing a successful chronic care strategy.

Korea's healthcare system is not well prepared to meet the changing needs of its population. Tackling chronic diseases requires better coordination, continuation across health care

¹ The University of Suwon, Gyeonggi, South Korea

² Korea Institute for Health and Social Affairs, Sejong, South Korea

Corresponding Author:

Sujin Kim, Korea Institute for Health and Social Affairs, Sejong 30147, Korea.
Email: sujinkim@kihasa.re.kr



services, and health promotion and prevention. The community health care infrastructure is skewed towards the provision of inpatient and outpatient care services.¹⁰ Since gate-keeping is not strictly enforced, patients can use healthcare services in any type of hospital with relative ease, which hinders care continuation and coordination¹⁰ and may result in poor outcomes, such as high rates of diabetes-related hospitalization.¹¹ A community-based primary-care chronic disease management pilot project was implemented¹² in response to the emerging challenge of chronic diseases in South Korea.¹⁰ While the project includes comprehensive services such as care planning and education, it covers only hypertension and diabetes patients in several regions.¹²

Despite the increasing burden of chronic illness and the recent emphasis on patients' perspectives in the healthcare system, studies in Korea have conducted limited investigations into the perceptions of patients with chronic diseases, with only 1 study conducted in 2014.¹³ Understanding and incorporating the public's views and perceptions help to address the emerging challenge of chronic diseases in South Korea. This study aims to analyze patients' experiences and examine patients' unmet needs regarding chronic care in South Korea.

Method

Study Setting

Focus group interviews (FGIs) were conducted on patients who have had chronic diseases, such as hypertension, diabetes, or hyperlipidemia, for more than 3 years.

Participant Recruitment and Data Collection

Participants were all 45 years of age or older with more than one chronic disease and were mainly using primary care clinics for chronic disease management. The FGIs were conducted from July to September of 2021. Each group consisted of 2 to 4 patients, and a total of 23 people participated. The interviews were conducted face-to-face by inviting participants to an allowed space where quarantine rules such as wearing facial masks and social distancing were strictly observed. We used semistructured questionnaires that were focused on patients' care experiences and expectations for patient-centered care management. Two researchers participated in the FGIs, and each interview took one hour to one and a half hours. All of the interviews were recorded and transcribed for analysis. Table 1 shows the patient demographics.

Ethical Considerations

All participants provided free and informed consent before the interviews. Patient confidentiality was maintained throughout the study. Ethical approval was obtained from the Korea Institute for Health and Social Affairs.

Data Analysis

Theme analysis was conducted based on the verbatim transcripts from the FGIs. Texts were extracted by setting "patients' experience of chronic disease care" as the main unit of code. To categorize the themes, we read the transcripts repeatedly and derived meanings inductively. The codes

Table 1. General Characteristics and Illness Information of Participants.

No	Participants	Gender	Age	Type of illness (order of diagnosis)	Duration of illness (years)
1	P1	M	51	Diabetes, hyperlipidemia	4
2	P2	F	45	Diabetes	10
3	P3	M	55	Diabetes, hypertension	3
4	P4	F	67	Hypertension, diabetes, hyperlipidemia	10
5	P5	F	67	Hyperlipidemia	5
6	P6	F	60	Hyperlipidemia	3
7	P7	F	63	Diabetes	6
8	P8	M	63	Hypertension	27
9	P9	F	50	Hypertension, hyperlipidemia	9
10	P10	M	55	Diabetes, hypertension, hyperlipidemia	11
11	P11	M	59	Diabetes, hypertension, hyperlipidemia	9
12	P12	M	55	Diabetes, hypertension, hyperlipidemia	21
13	P13	F	53	Hypertension, diabetes	15
14	P14	M	59	Hypertension, diabetes	7
15	P15	F	63	Hypertension, hyperlipidemia, osteoporosis	7
16	P16	F	65	Hypertension, hyperlipidemia, osteoporosis, arthritis	11
17	P17	M	65	Hypertension, hyperlipidemia	3
18	P18	F	65	Hypertension, hyperlipidemia, diabetes	15
19	P19	F	66	Hypertension, angina	15
20	P20	F	66	Hypertension	16
21	P21	F	57	Hyperlipidemia, osteopenia	3
22	P22	M	60	Hyperlipidemia	3
23	P23	M	55	Chronic neurovascular headache	10

generated by each researcher were shared to confirm the agreement between the 2 researchers after coding.

Results

A total of 11 themes emerged and were clustered into 2 categories: Provider-patient interaction experience and community and health system experience (Table 2).

Patient-Provider Interaction Experience

Doctors only prescribe medicine. Most of the participants were diagnosed with chronic diseases through a national health screening program. They visited local clinics after being diagnosed and began treatment for chronic diseases as they would acute illnesses in the clinics or hospitals. Participants reported that most doctors emphasized taking medicines, but didn't seem to care about other treatment methods, such as sharing information, providing education about their disease, and tests to prevent complications.

The doctor said, my case is on the borderline now, so he said "You should start taking medicine right now!" without any other explanation. I had expected his advice about exercise or diet for early diabetic patients, but he said nothing but "The more anxious you are, the worse your blood sugar level will be.—P18

When I was first diagnosed, I didn't have proper knowledge of diabetes. Of course, the nurse explained diabetes with the booklet for about 15 min, but it was only a very formal story that everyone knew.—P1

Doctors who provide conventional advice. Even though participants had a consultation, they felt that the doctors said the

same thing every time without sincerity. The doctor's perfunctory medical advice was not sufficient or effective enough to motivate the patients to modify their lifestyles.

So even though they temporarily have a positive attitude toward managing the diseases at the moment they meet a doctor, their original daily routines don't change much after all.

They say always the same words, "Take medicine regularly," or "Do exercise every day." Those words are too conventional. He didn't specifically explain for me how to lose weight or what to do with my diet in detail.—P21

It's almost the same words every time I visit him. "Don't drink," "Don't smoke," "Do exercise," or "Watch your weight." Those are conventional. Then I say, "Okay" and then come out of his office, and do whatever I want.—P17

Doctors who do not respect the patient's opinion. Participants expected a doctor to listen to and sympathize with patients' difficulties and concerns and to respect their opinions. They believe it is a patient's right to determine whether there is proper explanation and respect, not a doctor's.

Patients can tell their doctors, "In my experience, I want to keep taking the old medicine because the new one doesn't seem to suit me." But some doctors respond that patient challenges the doctor's authority.—P2

Long wait times and inadequate consultations. Many participants indicated that their doctor looked very busy and was in a hurry to see other patients. As a result, they were unsatisfied with the consultation time and felt the doctor was a "person who just prescribes medicine."

Since the waiting line is always long at the clinic, I can recognize that the doctor is trying to meet a patient as short as possible. I wish there were some new ways like reservation or patient quota system, because I want to talk to a doctor without time pressure.—P18

I'm getting nervous while meeting my doctor in his office since there are patients waiting for their turns outside the room. It seems that I have to finish my turn quickly and hand over the next. Then I always forget to ask something about the disease care.—P16

Lack of personalized care. Most participants want a doctor's management service for their data and believe that this is an important element in trusting their doctors. Monitoring and providing an individually customized care plan and feedback should enhance the therapeutic relationship between doctors and patients, resulting in positive outcomes.

I think the doctor has to manage them differently depending on the patients' own characteristics or data, but now doctors

Table 2. Patients' Experience for the Chronic Disease Management.

Theme categories	Themes
Patient-provider interaction experience	Doctors only prescribe medicine Doctors who provide conventional advice Doctors who do not respect the patient's opinion Long wait times and inadequate consultations Lack of personalized care Freedom to select another doctor
Community and health system experience	Struggling alone Commercial media and folk remedies Lack of IT technologies for care Demanding visiting services Lack of collaboration in the community

prescribe drugs based on general figures. I don't think it's personalized, and that kind of treatment doesn't seem to work for me either.—P14

Freedom to select another doctor. Some patients choose doctors by visiting several clinics or hospitals until they meet a doctor who satisfies their needs. One participant shared how this was not desirable, but their only option.

I expected he tells me the overall plan, but "Let's meet next time." That's all. I visited the clinic again and again, but the doctor said, "Let's meet next time," and that's it. He considered me only as a money-making partner. So, my conclusion was to change a doctor because doctors are everywhere. I hunted for another doctor. I know I'm a "bad patient" but I can't help it. As far as I know, this is the only way I can do.—P21

Community and Health System Experiences

Struggling alone. Chronically ill patients often struggle to self-manage their conditions, such as with an appropriate diet and regular exercise. Many hope that health experts will provide medical advice, appropriate feedback, and education.

I don't know exactly what's the best way, but for me, I want stronger professional intervention. I know whether it's hypertension, diabetes, or any other chronic disease, the patient has to manage it himself. But I can't do it alone. The patient may be in an environment where he or she can't do well even if he or she wants to.—P13

If there was a health self-help group in the community, I could share the experiences of people who succeeded in managing their chronic diseases, listen to and learn from others. And it would be even better if a doctor was at the meeting sometimes and answered the questions.—P3

Commercial media and folk remedies. Chronic patients receive information regarding health and chronic diseases from various sources, including the TV or internet. Respondents recognized that such information is commercial, and may be inaccurate and unreliable. However, they continuously sought information and products because of their concerns and interest in health. They often use these products in parallel with their doctor's prescription, which may have negative consequences.

Whenever I watch TV, something about chronic illness always catches my eyes. Sometimes I change another channel, it sells health supplements related to what was broadcasted about the same issue a while ago. I fall for it and buy them in the end.—P21

At first, I chose oriental moxibustion by myself. When I felt that folk remedy alone was not effective, I visited a doctor and started taking medicines. I still have a lot of interest in

folk remedies, but my doctor doesn't trust them, so I'm secretly doing it without telling him.—P8

Lack of it technologies for care. Some patients suffering from chronic condition answered that it is not easy for them to visit a hospital and see a doctor regularly because of their social and economic activities. They believe a remote care system would allow patients to receive appropriate feedback from the experts "anytime" and "anywhere."

It's not easy to make time for visiting a doctor regularly. So, I hope there is an online platform where I can communicate whenever it's necessary. Also, I think it would be nice if I could share my data with my health experts and get feedback in charge from time to time, saying, "You're managing it so well, but try this method."—P14

Demanding visiting services. Participants' demands for chronic disease care are various. Many were dissatisfied with the current provider-centered model and wanted the services to shift to a patient-centered approach, such as visiting services.

There are many people, like me, who have difficulty coming to the clinic because of limited mobility. Moreover, to manage chronic disease effectively, I think health professionals should check the patient's living environment when they visit. But most clinics or doctors don't care about it.—P4

... Even if he has a care coordinator, it's a little bit ... passive way, because it only applies to patients who come to his clinic. Therefore, it would be better to do it in connection with community resources such as home visit nurses or community wellness center.—P1

Lack of collaboration in the community. Participants want local doctors to manage their care and connect with various community resources, including public health centers. To prevent unresolved complications or complex chronic illnesses at local clinics, referral systems among hospitals should be more convenient.

I moved to this town from town A 7 months ago. When I lived in town A, there were two nurses who worked at community service center and visited me for caring. But nobody contacted me after I moved here.—P12

If I need some disease-related tests, I have to go to a bigger hospital by myself. If the system is well established, I hope that there is a system that can be solved directly by connecting with university hospitals in primary clinics.—P23

Discussion

Most participants in our study reported poor interactions with their health care providers, especially doctors. In particular,

patients reported that healthcare providers were only interested in dispensing medication and providing short, conventional advice and did not listen to their opinions. A previous study suggested that these problems came from acute care-oriented and fragmented healthcare systems.¹³ More specifically, multiple factors at the provider, organizational, and system levels may cause these problems. At the provider level, most physicians in local clinics are specialists, since primary care provider qualifications are not regulated.¹⁴ They are less likely to understand the roles of primary care providers and more likely to focus on curative and specialty care, underusing preventive, comprehensive, and community-oriented care.¹⁵

At the organizational level, physicians need to be more involved with nonphysician professionals to conduct routine assessments and preventive tasks and to provide the counseling and support necessary for self-management.^{4,16} However, the majority of local clinics are solo practices in Korea,¹⁰ which makes it difficult for physicians to work in teams and to provide comprehensive care. At the system level, the current reimbursement mechanism is optimized for acute care rather than chronic care.^{4,9} Based on fee-for-service payment, productivity measures focus on the number of visits and technical procedures.⁴ Providers are generally not rewarded for comprehensive assessments, counseling, and educational activities,⁴ and positive outcomes.^{17,18}

Our findings show that community resources are not well mobilized. The care of patients with chronic conditions cannot be limited to their contacts with health care providers. These patients need support at home, work, and in the community, where they spend most of their time.¹⁶ First, developing self-management skills and lifestyle changes fundamental to chronic disease care^{16,19} requires a whole-system approach and community resources beyond individual healthcare providers.¹⁹ Group and community interventions, such as a weight-loss program, combined with professional support may enhance patients' self-management skills.¹⁹ Next, people with chronic conditions living in a community require visiting and social services.²⁰ Although several programs have been implemented in Korea, they provide services for a limited group,²¹ and do not have adequate human resources.²² Lastly, fragmented services and a lack of coordination are more serious problems in Korea, where primary care is not well established than in other countries.¹⁵ Korean physicians also indicated that coordination and comprehensiveness are lacking in primary care.²³ Payment and healthcare delivery systems should be developed to enhance community-based coordinated and integrated care.

Some participants in our study emphasized the use of information technology. Information regarding patients, their care, and their outcomes are essential to improving chronic care.⁴ The electronic patient care record may support communication between health care professionals and reduce errors.²⁴ In addition, the information can be used to compare provider performance.^{24,25} Information

technology may enable home care through telecare and telehealth applications.⁹ In Korea, the National Health Insurance Service has given a financial incentive to providers by reviewing prescriptions and treatment,²⁶ but other providers such as nurses and clinical nutritionists have limited access to this information, which may prohibit care coordination. Establishing an electronic patient care record may cause privacy concerns, but safeguards could ensure patient benefits.^{10,25}

This qualitative study explored patients' experiences of chronic disease management under the current Korean healthcare system, especially primary care. There are several policy-evaluating studies from the perspectives of the policymakers or healthcare providers, but few studies have evaluated the chronic disease care system from the viewpoint of the patients and service users. This approach will help policymakers establish a more patient-centered chronic care system.

Limitations

One limitation of this qualitative study is the small sample size of patients. Future research should aim to gather a larger number of patient perspectives regarding their care experiences and recommendations for enhancing healthcare delivery in alignment with advancements in information technology. In addition, our findings may not represent the diverse perspectives of those with chronic illnesses. Nevertheless, our findings are good evidence for developing future policies.

Conclusion

A fundamental change in the paradigm of the Korean healthcare system is required for successful chronic disease management and desirable health outcomes. Our findings suggest that the existing fee-for-service payment and healthcare delivery system should be more patient-centered. In addition, programs like community-based primary-care chronic disease management initiatives should strive to incorporate the perspectives of patients with chronic diseases. New policies are more likely to succeed when they proactively address the diverse needs of patients with chronic conditions.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.


Ethical Approval

Ethical approval was obtained from the Korea Institute for Health and Social Affairs.

Informed Consent

All participants provided free and informed consent before the interviews. Patient confidentiality was maintained throughout the study.

ORCID iD

Sujin Kim, PhD  <https://orcid.org/0000-0002-4251-6318>

References

- World Health Organization. *World health statistics 2021: Monitoring health for the SDGs, sustainable development goals*. Geneva: World Health Organization; 2021.
- Korea Disease Control and Prevention Agency. 2021 chronic disease status and issue - chronic disease fact book. Korea Disease Control and Prevention Agency; 2021.
- Nolte E, Mckee M. Caring for people with chronic conditions: an introduction. In: Nolte E, Mckee M (eds) *Caring for People with Chronic Conditions—A Health System Perspective*. Open University Press; 2008:1-14.
- Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. *Milbank Q*. 1996;74(4):511-44.
- Bombard Y, Baker GR, Orlando E, et al. Engaging patients to improve quality of care: A systematic review. *Implement Sci*. 2018;13(1):98.
- Paddison CA, Saunders CL, Abel GA, et al. How do people with diabetes describe their experiences in primary care? Evidence from 85,760 patients with self-reported diabetes from the English General Practice Patient Survey. *Diabetes Care*. 2015;38(3):469-75.
- Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? *Eff Clin Pract*. 1998;1(1):2-4.
- World Health Organization. Noncommunicable D, Mental Health C. Innovative care for chronic conditions: building blocks for actions. A global report. Geneva: World Health Organization; 2002.
- Ham C. The ten characteristics of the high-performing chronic care system. *Health Econ Policy Law*. 2010;5(Pt 1):71-90.
- OECD. OECD reviews of health care quality: Korea - raising standards. Paris: OECD Publishing; 2012.
- OECD. Health at a Glance 2019. 2019.
- Song E, Kim Y-E, Ji S. Impact of a primary health care chronic diseases management pilot program. *Korean J Med*. 2021;96(1):7-12.
- Kang M, Kim J, Bae S-S, Choi Y-J, Shin D-S. Older adults' perception of chronic illness management in South Korea. *J Prev Med Public Health*. 2014;47(4):236-43.
- World Health Organization. Regional Office for the Western P. *Republic of Korea Health System Review*. Manila: WHO Regional Office for the Western Pacific; 2015.
- Cho Y, Chung H, Joo H, et al. Comparison of patient perceptions of primary care quality across healthcare facilities in Korea: A cross-sectional study. *PLoS One*. 2020;15(3):e0230034.
- Nuno R, Coleman K, Bengoa R, Sauto R. Integrated care for chronic conditions: The contribution of the ICCC framework. *Health Policy*. 2012;105(1):55-64.
- Jeong H-S. Designing an effective pay-for-performance system in the Korean National Health Insurance. *J Prev Med Public Health*. 2012;45(3):127-36.
- Jeong H, Lee H, Lee JH, Lee T. Payment reform for the improvement of primary care in Korea. *J Korean Med Assoc*. 2013;56(10):881-90.
- Rijken M, Jones M, Heijmans M, Dixon A. Supporting self-management. In: Nolte E, Mckee M (eds) *Caring for People with Chronic Conditions—A Health System Perspective*. Open University Press; 2008:116-42.
- Dubois C-A, Singh D, Jiwani I. The human resource challenge in chronic care. In: Nolte E, Mckee M (eds) *Caring for People with Chronic Conditions—A Health System Perspective*. Open University Press; 2008:143-71.
- Yi YM, Park Y-H, Cho B, et al. Development of a community-based integrated service model of health and social care for older adults living alone. *Int J Environ Res Public Health*. 2021;18(2):825.
- Lee G, Yang S-J, Woo E. Past, present, and future of home visiting healthcare services based on public health centers in Korea. *Journal of Korean Public Health Nursing*. 2018;32(1):5-18.
- Lee JY, Eun SJ, Ock M, et al. General internists' perspectives regarding primary care and currently related issues in Korea. *J Korean Med Sci*. 2015;30(5):523-32.
- Manca DP. Do electronic medical records improve quality of care? Yes. *Can Fam Physician*. 2015;61(10):846-51.
- Melnick ER, Sinsky CA, Krumholz HM. Implementing measurement science for electronic health record use. *JAMA*. 2021;325(21):2149-50.
- Kim SM, Jang WM, Ahn HA, Park HJ, Ahn HS. Korean National Health Insurance value incentive program: Achievements and future directions. *J Prev Med Public Health*. 2012;45(3):148-55.