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Transforming the Patient-Provider Relationship through Digitalized Peer Support in Japan in Japan

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Abstract

The recent explosion in online dissemination of health-related information, and its availability to more and more people around the world, have led to a situation in which both health care providers and patients are accepting new roles. The traditional asymmetrical relationship between health professionals and patients, who differ greatly in knowledge and in which the health professionals are in a dominant position, is changing to one in which they are on equal footing and in a collaborative relationship. With the spread of the Internet, medical knowledge that used to belong to healthcare professionals is now accessible to patients. Patients who are fluent in English can obtain the latest medical information from English-language literature before healthcare professionals do, translate it into their own language, and introduce it to their healthcare professionals. Patients who were previously physically unable to move around are now connected online, engaging in patient-group activities and empowering themselves through peer support. Thus, the advancement of digitalization has the potential to change the way patients live, including their relationships with health care providers. This paper examines the transformations toward new roles for healthcare professionals and patients, with a focus on Japan. We examine the situation in which the promotion of digitalization is one of the driving forces that is accelerating these changes further.

Keywords: sick role, patient, healthcare providers, digitalization, peer support

Background

Online dissemination of health-related information has exploded in recent years, making it readily available to more and more people around the world, as Mitchell and Kang predicted.[1] This trend is likely to lead to a situation where both healthcare providers and patients will assume new roles. The traditional asymmetrical relationship between health professionals and patients, in which health professionals are in a dominant position, with adequate knowledge, and patients have a significant knowledge gap, is shifting to one in which health professionals and patients are on a more equal footing and have the potential to collaborate.

The Japanese novel *The White Tower,* by Toyoko Yamazaki (1965) mainly focuses on a struggle between doctors over the selection of professors at a medical school.[2] It also depicts a hospital organization dominated by authoritarian doctors, whose tremendous authority and disregard for patients results in misdiagnosis and lack of informed consent. *The White Tower* has been adapted as a television drama in 1967, 1978, 1990, 2003, and 2019. (It was also adapted as a television drama in South Korea in 2017.) Each new version reflects the healthcare situation of its time. It depicts healthcare practice in postwar Japan, including the relationships between patients and healthcare providers, the relationships between community physicians (as private practitioners) and specialists at university hospitals, and the traditional hierarchical roles and values of physicians and patients. However, examining the actual situation of healthcare in Japan reveals the emergence of new roles for both healthcare professionals and patients.

In the mid-20th century, after accusations of medical experimentation without the consent of patients by Henry Beecher in 1966 and the revelation of the Tuskegee syphilis study in 1972, a bioethics movement arose in the United States. It focused on the importance of the patient's right to self-determination and informed consent in healthcare.[3-7] The influenced of this American trend in Japan emerged in the 1990s. Since then, the importance of respecting patients' rights has been advocated and the need for patients' self-determination has been widely recognized. The Japanese healthcare system has come to respect patients' rights, including the right to self-determination, and informed consent for patients has become mandatory. This shift occurred due to the introduction and popularization of bioethics, mass media reports on the frequent occurrence of medical accidents, the participation of multiple professions in healthcare, and the demand for transparency in healthcare.[8]

Patients in Japan are no longer only entrusting decisions about medical treatment to healthcare professionals, but are also seeking to better understand their own bodies and healthcare, and to take an active role in the healthcare system.[9] They are increasingly becoming active participants in the health care system. These trends are prompting changes in the roles of health professionals and patients.

One important driving force furthering these changes is the recent push toward digitalization in healthcare.1 Digitalization of healthcare is having a variety of impacts, including increased use of telemedicine for remote diagnosis and treatment, transportation and delivery to improve the quality of care, improved access to healthcare services, and increased use of big data in healthcare. For patients, digitalization allows them to access their medical records and communicate with healthcare providers via email, online portals, and apps without having to visit a healthcare facility.10 Such virtual access to healthcare via the Internet and telecommunications has high potential in both high-income countries and in emerging and low-income countries, given the global cell phone adoption rate.[1]

Thus, the advancement of digitalization has the potential to change the way patients are and their relationships with healthcare providers. With the global phenomenon of widespread use of the Internet, medical knowledge that was once only the domain of the medical profession is now accessible to patients. Patients are also using the Internet to connect and share medical information with each other. For example, in Japan, patients who were previously physically unable to travel are now connecting online and engaging in patient group activities and empowering themselves through peer support.[11]

The digitalization of healthcare has also contributed to the development of a more patient-centered society. In Japan, many patients have begun to share their illness experiences through blogs and social networking services (SNS). In addition, peer support has become a worldwide phenomenon through the Internet, both within and across national borders.[12] The narrow definition of peer support is mutual interaction and support among people with the same illness or disability, but a broader definition includes people surrounding patients, such as healthcare and welfare professionals.[13] In the latter definition, peer support becomes a form of communication between patients and healthcare providers. Peer support is expected to help experienced patients/participants bridge communication gaps between patients and healthcare professionals, leading to improved quality of life.[14]

This study examined: whether digitalization is facilitating the phenomenon of peer support, in which patients interact with and empower each other; whether changes created by digitalization are changing the way patients interact with healthcare providers; and whether digitalization could transform traditional patient and healthcare professional roles to the extent that it fosters a new form of healthcare, in which experienced patients proactively participate in healthcare to support less experienced patients, and healthcare providers and patients respect each other on an equal footing.

What is the "sick role?"

When a person is physically ill, he or she not only experiences physical pain and disability, but also emotional instability and a sense of hopelessness. What, then, is the traditional relationship between patients and health professionals, especially physicians? This is the topic of numerous sociological explorations.

Sociologist Talcott Parsons defines the roles of the medical professional and the patient in his work *The Social System*.[15] First, Parsons considers the physician as a prototype of a "profession." He argued that the physicians are motivated to work for the benefit of others (altruism). However, this leads physicians to adopt a paternalistic orientation, making important decisions on behalf of others, rather than respecting the autonomy their patients. Furthermore, Parsons defines "the patient" as being in a deviant state in which the person is not responsible for his or her own condition and is in need of assistance. He formulated the concept of the "sick role" as society's expectations of a sick person, including being exempted from their normal social roles until they recover from their illness.[15]

The sick role is defined by two obligations and two rights. Since falling ill is a deviation from the normal social condition, the sick person is expected by society to 1) recover from the illness as quickly as possible, and 2) return to normal conditions. These are the two obligations. The "sick role" is beneficial to the ill person because it 1) allows him or her to be away from routine tasks, and 2) to receive healthcare—these are the two rights. However, in the case of chronic illness or disability, the person may never be "cured" or able to return to his or her former state, resulting in deprivation of work and social participation for an extended period of time. In contemporary societies, which emphasize being healthy and independent, people with illnesses and disabilities are thus "stigmatized."

Despite some valid criticism, Parsons' depiction of the roles of the medical professional and the sick captured reality with some accuracy.[9] The "traditional" patient-provider relationship in healthcare, especially in Japan, was indeed a paternalistic one. Another medical sociologist, Eliot Friedson, published "Professional Domination in Medicine" in 1970 [16]; it was translated into Japanese in 1990. This work was widely accepted as representing the situation in Japan at that time. A number of other studies published in the 1990's by Japanese medical sociologists also discussed the asymmetrical power structure between doctors and patients in medicine, and the hierarchies among medical professionals.[17-19]

Parsons and Friedson presented the relationship between the medical professional and the ill person as either a conflictual relationship or a relationship between an adult and a child. In contrast, Szasz and Hollender showed that the relationships differed depending on the patient's situation.[20] They developed three models of the doctor-patient relationship, corresponding to three medical conditions of the patient: 1) coma or severe mental illness; 2)

acute infection; and, 3) chronic illness. In the first case, coma or severe mental illness, the doctor-patient relationship is viewed as an "activity-passivity" model, like that between a parent and an infant. In case #2, acute infectious diseases, the doctor-patient relationship is viewed in a "guidance-cooperation" model, like that between a parent and an adolescent child. The third case, chronic disease, results in a "mutual participation" model, as between adults.

In contrast to the historical "sick role," a phenomenon is currently emerging that we are calling the "new sick role". In this conception, the person has an illness but lives free from stigma and discrimination, continues working and doing what they want to do without giving up, and remains financially stable while undergoing treatment. What is behind this phenomenon? We believe that it stems from how people who are living with the same disease have gathered together, to form patient associations, to educate society about their disease, and to appeal for the establishment of social systems necessary for continued schooling and employment. This evolution of the "new sick role" is similar to Michael R. Reich's analysis of the victims of pollution-related diseases who created a new identity by grouping together, gaining strength from their large numbers, and working together to achieve their goals of redress.[21]

Studies on the linkage of collective action by patients with health care reform began in the English-speaking world [22-23] and in Japan as long ago as the 1950s, with movements by groups of patients with tuberculosis and Hansen's disease to end discrimination against the disease and improve treatment in hospitals. Groups of Japanese patients with Hansen's disease won the repeal of the Leprosy Prevention Law, which had legalized segregation, as a result of decades of campaigning.[24]

In Japan, various patients groups have formed in recent years, for patients with various types of cancer, stroke, cardiovascular disease, renal disease, intractable diseases and myalgic encephalomyelitis.[25] The advocacy activities of these patients' associations are noteworthy, and they are trying to change the healthcare system and laws, as well as social consciousness. For example, when the Act on Cancer Control and Prevention (2007) and the Act on Stroke and Cardiovascular Diseases (2018) were enacted, medical and social services were expanded by revising governmental insurance coverage fees.

While consumer rights movements, the advancement of bioethics, and the improvement of patients' health literacy are factors that have promoted patients' empowerment, the recent development of digital technology is also important.[12] Patients who previously had limited access to medical knowledge are now able to obtain up-to-date medical information through the widespread use of the Internet. It has also become relatively easy for patients to learn about trends among patients in other countries. Before the advent of the Internet, patient associations for those with physical disabilities that prevented them from traveling previously offered limited connection. Now, however, patients can connect and exchange information through online conferencing systems. Over the last three years, the digitalization of patient

associations has progressed rapidly as a result of the COVID-19 pandemic. In this context, the patient profile has changed dramatically. This study examines how the Internet and digitalization contribute to strengthening and maintaining the sustainability of connections as people with illnesses and disabilities establish identities, redefine the "new sick role", and remake the relationships with healthcare providers.

Research Methods

This study employed a mixed-methods approach to examine the transformation of the relationship between healthcare professionals and people with illnesses and disabilities as a result of the impact of digitalization. The study underwent an ethics review, and details are provided at the end of the paper.

The study was conducted with the cooperation of three patient groups, labeled “A,” “B,” and “C.” These patient groups were selected as research collaborators because the members have a range of diseases and disabilities, their activities take place in the north, center, and south of Japan, and the leaders of each group understood the research and were willing to actively participate.

Patient group A began as an association of young stroke patients. It was established in 2016 as a voluntary organization and certified as a non-profit organization in 2017. Its activities include “café” gatherings and sports events for people with disabilities. Over time, patients with other diseases and disabilities, such as muscular dystrophy and ALS, began to participate. A has approximately 40 members and is based in Obihiro, Hokkaido, in northern Japan.

Patient group B is a community-based association of patients, regardless of disability or disease, which was established as a general incorporated association in 2019. In addition to providing peer support and organizing events, it also links life science companies with patients to reflect patients’ voices in the development of medicines and medical technologies. B has approximately 20 members and is based in Tokyo (in central Japan).

Patient group C is also open to people with all diseases and disabilities. Healthcare professionals, especially occupational therapists, are also core members of C. C holds social gatherings and events for its members. The unique feature of C is that the patients and occupational therapists pair up to teach about the patient experience at training schools for health care professionals nationwide. C has approximately 20 members and is based in Fukuoka and Oita, Kyusyu, in southern Japan.

As noted, the research methodology combined elements of quantitative research and qualitative research (interview and observation). Data were primarily collected in two ways: 1) a survey was conducted on the implementation of patient associations and peer support in

Japan; and 2) observations of the experience of digitalization of peer support (implementation of peer support in a virtual reality space) by members of the patient associations who agreed to interviews.

The online questionnaire surveyed patients' association about their activities for patients and healthcare professionals throughout Japan. It asked about: the conditions of patients' association, their activities, and their hopes for any kind of healthcare. The questionnaire was developed in consultation with representatives of the three patient groups, an occupational therapist, a data scientist, and a sociologist. The questionnaire was administered as an anonymous online survey using Google Forms.

Only participants who had been fully informed about the survey, who had been promised anonymity, and who voluntarily agreed to participate were able to answer the online questionnaire. Respondents included patients, persons with disabilities, and healthcare professionals. They were recruited widely through SNS and several healthcare-related e-mail newsletters. We also asked for the cooperation of three organizations (A, B, and C), healthcare-related organizations, and healthcare-related academic societies to assist us in recruiting participants.

The implementation period was from May to August 2022. We received 210 responses from people with illnesses or disabilities and 211 responses from healthcare professionals.

The second method of data collection was through questionnaires and interviews with participants in a virtual space. The initial survey asked members of the three patient groups to voluntarily experience and share their impressions of a digital meeting space using the "XRCC: Cross Reality Conference Cloud" (which was provided by MPUF: Microsoft Project Users Forum). The XRCC utilizes avatars in a metaverse space that combines the real world and virtual world. Six trials were conducted in which five to six members of the patient groups entered the XRCC space between December 2021 and November 2022. Data for this study were collected by observing their interactions, as well as conducting questionnaires and interviews in which the participants were asked to evaluate their digitalization experiences.

Results

Survey findings

Various interesting results emerged from the survey. Table 1 presents basic characteristics of online survey participants.

Table 1. Basic characteristics of online survey participants

	Respondents	Age	Sex (M:F)	Status	Participation in Patient Groups	Of those who have participated in online
Person with Illness or disability	210	Mainly 50s and 60s	6 : 4	Physical disability, intractable disease, cancer, etc	73.3%	64.8%
Healthcare professionals	211	Mainly 40s and 50s	6 : 4	Nurse, Doctor, OT, etc.	37.4%	70.9%

The peer support by patient groups was found to have both benefits and challenges (Table 2). The advantages of peer support included: feeling more comfortable (26.6%), being able to face the disease (19.2%), improved communication with healthcare providers (17.8%:), and relief of worries (16.4%). On the other hand, the most common disadvantages of peer support were: worries were not resolved (23.2%), did not feel better (21.1%), did not change the relationship with healthcare providers (19.7%), and could not face their illness (17.6%).

We found that patient associations are steadily coming online. Of the patients who responded, 73.3% were members of a patient group—of these, 40% belonged to more than one patient group. Two-thirds (66%) of patient respondents said they had provided peer support, of which 64.8% said they did so online. The most common electronic devices used were computers (93.5%), smartphones (34.8%), and tablets (15.2%) (multiple responses were allowed).

A multiple-answer question compared online to face-to-face peer support. The most frequent responses were: “I am glad I don't have to travel to the venue because I am physically unable to travel” (52.2%), “It is the same as face-to-face” (34.8%), and “I don't feel nervous” (13.0%), which were characterized as advantages. However, a number of respondents said that they preferred face-to-face patient/participant meetings (43.5%).

Table 2. Advantages of peer support, among patients who have participated in peer support

feeling more comfortable	26.6%
being able to face the disease	19.2%
improved communication with healthcare providers	17.8%
relief of worries	16.4%

The healthcare professionals surveyed indicated that 37.4% of them support or participate in patient groups, and 70.9% said they participated in online patient groups. Providers’ evaluations of peer support were generally positive; participants replied that “they felt more comfortable” (84.1%), “they were better able to face their illness” (76.8%), “their worries were

relieved" (58.5%), "the willingness of the patients to undergo treatment improved" (53.7%), and "communication between the patients and healthcare providers improved" (40.2%) (Table 3). Among the providers, 19.5% agreed that peer support could reduce the burden on the healthcare staff.

Table 3. Advantages of peer support, among healthcare professionals who have participated in peer support

they felt more comfortable	84.1%
they were better able to face their illness	76.8%
their worries were relieved	58.5%
the willingness of the patients to undergo treatment improved	53.7%)
communication between the patients and healthcare providers improved	40.2%

Findings on virtual peer support

The findings regarding peer support in a virtual space indicated it has certain positive effects. Participants reported on their experiences with communicating with each other on the XRCC digital platform and using anonymous avatars to interact with patients, supporters (healthcare providers), and researchers (Table 4).

Table 4. Core participants during the trial

A	3	Stroke, Cerebral palsy, Muscular dystrophy
B	2	Kidney Disease, Intractable neurological diseases
C	5	Stroke(4), Muscular dystrophy
Supporters	3	healthcare providers(Occupational therapists, Nurses)
Researchers	3	Healthcare innovation, Bio-engineering, Sociology

Upon entering the XRCC space, each participant created an avatar, choosing a face, hair style, clothing, and gender according to their preferences. Thus each participant had a unique appearance (Figure 1). A female stroke survivor, who was a disco queen in her youth, dressed in a yellow mini dress and white boots. A male stroke survivor who had been a backpacker dressed in a sporty outfit. Some participants dressed in business suits, while others wore monster headdresses. In the lively virtual space, participants moved freely, walking around,

jumping, and chatting with other avatars. In the space, the participants experienced easy access to distant people, which was otherwise difficult due to geographical restrictions.

Fig. 1 Patients and researchers entering the virtual space as avatars

The participants reported several positive impressions of the experience: (1) anonymity, (2) novelty, and (3) the philosophical aspect.

(1) The use of avatars ensured anonymity. This allowed participants to overcome the need for patients to express their "true feelings" to each other, and difficulties consulting with each other because of their existing relationships. However, anonymity may assist the participants to overcome these problems.

(2) Peer support in virtual reality is novel. Even those participants who previously showed little interest or real reluctance to engage in peer support became curious and even interested in participating when the new technology was used.

(3) The participants were able to free themselves from the traditional “sick role” imposed by society. In the virtual space, patients were able to exist and interact with others as themselves. One of the participants said, "In the metaverse space, disability is cured in the subjective dimension.” That is, because everyone in the virtual space exists as an avatar (with diverse appearances), patients feel free from social prejudice. As a result, their self-esteem increases, and they feel more confident.

Based on the above, the introduction of online peer support using digital technology has the potential of removing the stigma of being a sick person, creating a different perception of people with illnesses and disabilities, and enabling them to have a new social role as people

who work on something new. This is both an acknowledgment of the importance of the experiential knowledge [26] of the patients and represents a change from the traditional "sick role."

However, several challenges were also noted in moving toward digitalization. The technology of the virtual space still has room for improvement, especially in terms of operability. One participant commented: "I see great potential, but I don't know exactly how people can connect with each other in the digital space," while another said, "While the experience of people who cannot functionally move will be expanded, I also felt the danger that people who can functionally move will be shut in." A third noted, "Being alone in the virtual space makes me anxious." Participants also expressed their opinions and doubts about the metaverse itself, especially its accessibility. Although the metaverse still needs to be improved, especially in terms of its accessibility, it is worth considering as a way to implement patient groups and peer support. The digitalization of patient associations has the potential to establish new values and shape a society that values diversity and promotes inclusiveness.

Discussion: Signs of Transformation in the Patient and Healthcare providers Relationship

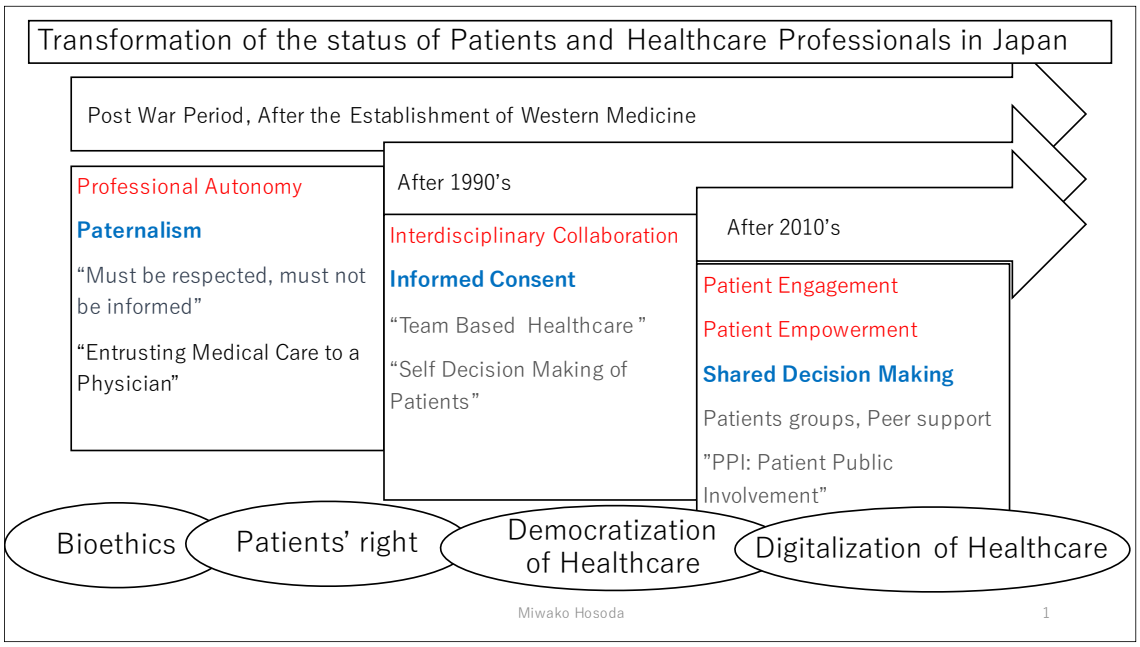
This study points out that peer support among patients was highly valued by both patients and healthcare professionals—and that digitalization has helped to revitalize patient associations and peer support in some aspects. In recent years, the importance of patient and public involvement (PPI) in healthcare and medical research has been demonstrated in Japan. For example, the Japan Agency for Medical Research and Development (AMED), an organization that plays a central role in research and development in the medical field and its environment, published a PPI guidebook in 2019 that describes the need for patient and public input into the medical research and clinical trial process.[27] A Ministry of Health, Labor, and Welfare expert panel also expressed that PPI should be promoted as an initiative to actively utilize the experiences, knowledge, and thoughts of patients, their families, and citizens for the research and development of future treatments and care, as well as for the management of healthcare.[28] All of these clearly formulated "the new role of the patient." This has also been shown in a study that examined how the implementation of digital technology in heart failure care can change the relationship between patients and health care professionals.[29] Patients, patient groups, and healthcare professionals all indicate that patients are changing due to digitalization, and that as a result, healthcare professionals are changing their views toward patients and changing their relationships with them.

Earlier work pointed out that it is inappropriate to position doctors and patients in an unbalanced relationship, such as that between the strong and the weak, or adults and infants.9 At that time, this view was regarded as close to "idealism." Today, however, this view is more

widely shared by healthcare professionals. Indeed, the current study was made possible by the mutual learning and co-creation of all people involved, including patients, healthcare providers, and technology developers. The resulting dialogues, between people who would never have met without these opportunities, show that digital technology has many unexplored possibilities in the field of medicine and health care.

This is where the "new sick role" emerges (Fig. 2). The next step is for healthcare professionals to learn from the "new sick role" to take on their own new roles. The new role healthcare providers take on could create an environment that welcomes patients as *part* of the healthcare team and promotes patient and citizen participation in healthcare.

Fig. 2: Postwar transitions in the status of patients and healthcare professionals in Japan



Activities related to peer support are currently not widely known among healthcare professionals in Japan. Of course, there are healthcare professionals who understand the benefits of peer support. However, most are either unaware of peer support or tend to perceive patient groups as groups of patients who criticize healthcare providers. Another challenge is that peer support is usually conducted on a volunteer basis, which means that there is little continuity and a lack of funding and human resources.

Regardless of the providers' viewpoints, the relationship between healthcare provider and patient is already transforming from a traditional paternalistic one to a more democratic and equal one. This trend could become a global movement, enabling connections not only within Japan but also with other countries around the world, since digitalization transcends geographical constraints. Through this process, new values and new roles for the various

participants in healthcare may be created, contributing to a society that respects diversity and coexists in harmony.

Ethical Declaration

The study was approved by the Research Ethics Committee of Seisa University on January 12, 2022, with reference number R-2021-72. For the online questionnaire survey, participants were asked to confirm their willingness to participate in the study before starting the online response. For the interviews, written informed consent was obtained from patients and health care professionals prior to their participation in the study. All methods were conducted in accordance with relevant guidelines and regulations.

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