Patient Preference and Adherence

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ORIGINAL RESEARCH

Influence of Participation in a Medical-Themed Science Café on Patient Activation

Yuta Okazawa[1], Hayato Kizaki[1], Nobuyuki Suzuki[2], Wakako Osaka[3], Satoko Hori[1,2]

[1]Division of Drug Informatics, Keio University Faculty of Pharmacy, Tokyo, 105-8512, Japan; [2]Patient Salon Association, Tokyo, Japan; [3]Keio University Faculty of Nursing and Medical Care, Tokyo, 160-8582, Japan

Correspondence: Satoko Hori, Division of Drug Informatics, Keio University Faculty of Pharmacy, 1-5-30 Shibakoen, Minato-ku, Tokyo, 105-8512, Japan, Tel +81-3-5400-2650, Fax +81-3-5400-2799, Email hori-st@pha.keio.ac.jp

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Purpose: This study aims to investigate the impact of a Science Café (SC) dealing with medical topics on participants' patient activation (PA), a concept that refers to patients' involvement in managing their own health, working with their healthcare providers, and maintaining their health.

Material and Methods: Semi-structured interviews were conducted with patients who had participated in a medical SC (n = 10) to identify the medical SC-associated factors that influenced PA. Through a questionnaire of medical SC participants (n = 23), the impact on PA and correlations with relevant psychological measures were quantitatively assessed.

Results: The interviews revealed three factors: "Experience & acceptance of chronic conditions", "Features of medical SC" and "Changes as a result of participation." The questionnaire results showed a positive correlation between PA and resilience and a negative correlation with decision regret.

Conclusions: Participation in a medical SC by people with illnesses can improve PA by improving knowledge and skills for self-management and increasing self-awareness of illness in a supportive environment. The study highlights the potential benefits of using medical SC as a strategy for healthcare providers to improve PA and health outcomes.

Keywords: self-management, psychological measures, patient community, supportive environment

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Introduction

For personal health management, treatment, and disease prevention, it is important for patients to be actively engaged in their own health management, and not rely only on the efforts of health care providers and the health care system. Patient activation (PA) refers to the aspects of health management from the patient's perspective. Activated patients recognize that they have significant roles in overseeing their health, working alongside health providers, and sustaining their well-being. They possess the knowledge to handle their health conditions, the ability to prevent health deterioration, and the skills to seek the right quality care.[1] It has been confirmed that persons with high PA not only have lower disease severity, but also show more positive healthcare behaviors, preventive behaviors, and the implementation of shared decision-making.[2–4] PA encompasses four phases: recognizing the significance of self-management, possessing the knowledge and assurance to act, actively working towards health betterment, and upholding healthy lifestyle alterations even under stress. The Patient Activation Measure (PAM) is a tool designed to gauge PA. The PAM measures these four classes and calculates a score on an interval-level scale from 0–100.[1] Some studies have also been conducted on means to improve PA, such as interventions through community pharmacy and telephone coaching programs, and these have been shown to improve PA.[5,6]

In this study, we hypothesized that a Science Café could function as a place to improve PA. A Science Café (SC) is a science communication activity in which scientific topics are explored interactively in a café, a place routinely used in people's daily lives. These SCs are often organized by academic institutions, researchers, or science enthusiasts aiming to bridge the gap between the scientific community and the public. The aim of SCs is not merely to disseminate scientific knowledge, but also to spark curiosity, provoke thought, and facilitate a two-way dialogue on contemporary scientific issues. The format and subjects of SCs can vary, ensuring they cater to diverse audience interests. While some SCs might

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feature a brief presentation by an expert, others might foster direct discussions between multiple speakers and the audience. Topics span a broad spectrum, from advanced technological advances to pressing global issues, and occasionally delve into the realms of medical care and health.[7,8] In a previous study, it was suggested that SCs dealing with medical and health topics may make participants reflect on their values and change their perspectives.[9] We hypothesized that such a transformation of values about health might also improve PA.

In line with our hypothesis, we collaborated with an organization named Patient Salon (PS), which is one of the patient communities. Here, the term "patient community" encompasses a broad spectrum, including patient associations, self-help groups, medical SCs, and related entities. PS sessions are conducted by people from the patient's perspective, rather than researchers or experts. This unique angle ensures that discussions are rooted in real patient experiences and challenges. These meetings, which have been held monthly more than 100 times, involve both patients and medical professionals. The primary activities in these sessions involve a guest speaker presenting a topic followed by discussions among the participants on various subjects such as "Views on Life and Death", "How to Handle Medical Information", and "How Patients and Their Families Can Make the Most of Their Lives". Given the similarities in the philosophies underlying Patient Salon and Patient Activation, we sought their cooperation in recruiting participants for this study.

In previous studies of the impact of patient-involved community activities on PA, it was found that participation of knee osteoarthritis patients and female patients with cardiovascular disease in peer support groups was associated with an improvement of PA.[10,11] However, these communities are characterized as self-help groups, and are qualitatively different from SC, in which participants from diverse backgrounds can explore a wide range of topics in a café embedded in the community.

Therefore, this study aimed to assess the impact of Science Cafés dealing with medical topics (medical SC) on PA and to clarify what factors in medical SC activities influence PA, using interviews and questionnaires.

Materials and Methods

Research Design

For this study, we used a mixed methods approach, combining semi-structured interviews and questionnaire methods. Interviews were conducted from August 2021 until June 2022, and the questionnaire was conducted in August 2021. The study targeted individuals aged over 18 years with chronic diseases or physical disabilities who participated in the previously mentioned Patient Salon (PS) that uses the medical SC format.

Interview

Interview Participants

Recruitment for the semi-structured interviews was primarily conducted within a Facebook group tailored for those who have attended PS events multiple times, aiming to gather insights from these regular participants. Interested participants responded to this post, and through the coordination of the Patient Salon Association, they were provided with a detailed information document about the study. After a review of this document, individuals who wished to participate were then formally approached by the researcher, YO, to schedule and conduct the interviews. Before initiating each interview, YO reconfirmed the consent of participants, ensuring they fully understood the study's objectives and procedures. This recruitment and consent process for the interviews took place from August 2021 until June 2022.

Interview Data Collection

Semi-structured interviews were conducted to understand the factors that affected the participants' PA and how their activities in the medical SC affected them. These interviews were conducted according to an interview guide (Appendix A.1) prepared for this purpose. Interviews were conducted by two researchers (main interviewer: YO, sub-interviewer: HK) either on Zoom or in a conference room on the Keio University Faculty of Pharmacy campus in a privacy-protected setting. The interviewers are YO, a Ph.D. course student at the Graduate School of Pharmaceutical Sciences, and HK, an assistant professor in the same department, both of whom hold a license as a pharmacist in Japan.

Data Analysis

All interviews were recorded with the consent of the participants. Verbatim transcripts were prepared from the recordings, and a thematic analysis was conducted. YO performed all coding inductively. The software used for this analysis was MAXQDA2018 (VERBI GmbH). Coding units were defined as a set of semantic units. Inductive coding was repeated, and codes were modified as appropriate in the process of the analysis. Themes were created based on the obtained codes. In this study, to enhance the trustworthiness of data analysis, the codes and themes generated by the first author (YO) were reviewed by another author (HK), and then modified and finalized by discussion between YO and HK. The process ended when it was confirmed that the generated themes did not change significantly. Data analysis was conducted at the Division of Drug Informatics in the Keio University Faculty of Pharmacy.

Questionnaire

Questionnaire Participants

The survey was disseminated in August 2021 to past PS participants, all of whom had attended at least once. The distribution was done using a mailing list and a Facebook group for those with previous PS participation. Among those who received the questionnaire invitation, some had also been approached for the semi-structured interviews. It should be noted that the questionnaire responses were anonymized, and the data from the interviews and the questionnaire were collected independently.

Questionnaire Data Collection

A blind questionnaire was conducted on Google Forms to explore the influence of the patient community on the participants and to assist in the analysis of the interview data.

As mentioned in the introduction, the term "patient community" includes diverse groups such as patient associations, self-help groups, and medical SCs. Many of our participants were involved in multiple such communities, making it essential to approach the survey in a comprehensive manner. This exploratory approach was crucial as pinpointing the influence of SC alone would be challenging, given the overlapping participation in multiple communities. In contrast, the semi-structured interviews specifically focused on understanding the unique impact and experiences related to SC participation.

The questionnaire design used PAM as the primary endpoint, and candidate factors tested for association with PA were community supportive functions, sense of community, self-efficacy, resilience, health literacy, decision regret, and attitudes toward healthcare providers (Appendix A.2). All the instruments used in this study were translated into Japanese or were Japanese versions. To ensure compliance with copyright requirements, permissions for the instruments were secured through one of three methods: obtaining licenses, seeking direct permission from the original authors via email, or confirming from user guides and respective repositories that no permission was required.

Measures

Demographic Data

As demographic data on the participants, the following information was obtained: age, gender, academic history, employment status, current disease, hospital visits, length of illness, and frequency of participation in the patient community, including patient groups, peer support groups, medical SC, and so on.

Patient Activation Measure (PAM)

The PAM is an instrument to measure an individual's knowledge, skills, and confidence in health care and is provided by Insignia Health.[1] In this study, we used PAM-10, which consists of 10 items in the Japanese version. Participants can respond to items with "disagree strongly", "disagree", "agree", "agree strongly", or "N/A", and the PAM score and level are calculated by Insignia Health. The PAM score is output as a continuous variable (0–100), with higher scores indicating more skilled and active self-management. The PAM level is calculated from the PAM score and consists of the four qualitatively different levels mentioned above.

Community Supportive Functions Scale (CSF)

The CSF is a scale that measures the supportive functions of the patient community and consists of 17 items on a 4-point

Likert scale.[12] The CSF was used to evaluate participants' perceptions of the helping function of the SC. Four domains comprise the CSF: "a place to communicate as a healthy person", "a place to have help from others", "a place to learn about the disease" and "a place to cultivate friendship." The higher the score, the greater the supportive function of the community.

Sense of Community Index (SCI)

The SCI is a scale that measures the sense of cohesion and trust as well as other feelings in a community and consists of 24 items on a 4-point Likert scale.[13,14,] The SCI was used to evaluate how deeply participants engage with the SC. Four domains comprise the SCI: "integration and fulfillment of needs", "membership", "influence" and "shared emotional connection." The higher the score, the stronger the sense of cohesion, trust, etc. that the participant has for the community.

Generalized Self-Efficacy Scale (GSE)

The GSE is a scale of self-efficacy that focuses specifically on personality traits and consists of 23 items on a 5-point Likert scale.[15,16] The higher the score, the higher the participant's trait self-efficacy.

Bidimensional Resilience Scale (BRS)

The BRS is a scale that measures self-efficacy and consists of 21 items on a 5-point Likert scale.[17] The BRS was used to understand innate resilience in participants and to assess acquired resilience through SC participation. The two domains, "innate resilience" and "acquired resilience", comprise the BRS. The "innate resilience" is further comprised of four subscales: "optimism", "control", "sociability" and "vitality." In addition, "acquired resilience" is comprised of three subscales: "attempting to solve a problem", "self-understanding" and "understanding others." The higher the score, the higher the participant's innate or acquired resilience.

European Health Literacy Survey Questionnaire (HLS-EU-Q)

The HLS-EU-Q is a scale that measures health literacy and was used to test the relation between the ability to use health information and PAM.[18,19,20] Three domains comprise the HLS-EU-Q: "health care", "disease prevention" and "health promotion." This study used a Japanese translation of HLS-EU-Q16, a shortened version of HLS-EU-Q47. The HLS-EU-Q16 consists of 16 items on a 4-point Likert scale, with higher scores meaning higher health literacy in participants.

Decision Regret Scale (DRS)

The DRS is a scale that measures distress or remorse after a healthcare decision and consists of 5 items on a 5-point Likert scale.[21] This scale was used to confirm the relation between PAM and the quality of decision making. Scores range from 0 to 100, with higher scores indicating more regret about medical decision-making.

Attitudes Toward Healthcare Providers Scale (AHP)

An original scale consisting of 10 items on a 5-point Likert scale was used to measure changes in attitudes and trust toward healthcare providers. Since the items in this scale were self-developed, the validity of this instrument has not been tested. Therefore, to examine the internal validity of this instrument, some items were deleted based on the criterion of $\mu-\sigma\leq 1$ or $5\leq\mu+\sigma$, considering the floor/ceiling effect. In addition, the instrument was examined for factor analysis by the maximum likelihood method and Promax rotation and was used for later statistical analysis.

Data Analysis

IBM SPSS Statistics 27 was used for data analysis. For each of the scales, internal consistency was examined by calculating Cronbach's α with $\alpha\leq 0.8$ as the criterion. The normality of each scale was confirmed by application of the Shapiro–Wilk test. Relations between the PAM-10 and each scale were analyzed using Pearson's correlations on the scales that assumed normality and Spearman correlations on the other scales. p values<0.05 were considered significant.

Ethical Approval

All methods were carried out in accordance with the Declaration of Helsinki. This study was approved by the Research Ethics Review Committee, Keio University Faculty of Pharmacy (approval number 210708-4). Before the interview or questionnaire response, each participant was provided with an explanation of the purpose and methods of the study, ethical considerations, and protection of privacy, and their informed consent was obtained in writing or digitally.

Results

Interview

Background of the interviewees

Consent to participate in the study was obtained from all ten recruited participants, with the background information shown in Table 1. Interviews were conducted on the dates requested by the participants, and one interview was conducted with each participant. All participants had previous experience of participating in patient communities other than the PS.

Science Cafés and Their Influence

From the analysis of the interview data, three themes were created regarding participation in medical SC and the effect it had on participants' PA. The three themes are "Experience & acceptance of chronic conditions", "Features of medical SC" and "Changes as a result of participation." The created codes and themes are shown in Table 2. These three themes have the relationships shown in Figure 1.

Experience & Acceptance of Chronic Conditions

This theme describes the journey of individuals as they struggle with the experience and acceptance of chronic conditions. It ranges from the periods before the onset of the condition, through the adversities and setbacks of the condition, to the transformative impact of these experiences. Below, we explore each category, illuminated by the direct voices of our participants.

Before Disease Onset

Before the onset of their diseases, participants often exhibited a lack of attentiveness to their health. There was a general tendency to remain passive, with little inclination to actively engage with healthcare providers or seek out medical knowledge. For instance, one participant mentioned that due to their busy work schedule, they could not prioritize their health. As a result, she did not visit a clinic even when she had minor illnesses.

> I was the kind of person who wouldn't go to a clinic even if I felt a bit unwell. Originally, I had severe allergies, and I suffered a lot from hay fever and rhinitis. I would only visit an otolaryngologist about once a year to get medicine for hay fever. I wouldn't go for minor complaints like stomachaches or headaches, and since I was generally healthy, I never had any serious health issues. Additionally, my job in the publishing industry was extremely busy, especially before deadlines, which often meant pulling all-nighters. Therefore, I hardly had any time to think about my health. - Participant G (Code: Did not actively engage with healthcare and healthcare providers)

Table 1 Background of the interviewees

	Gender	Age	Disease	Duration of Disease	Frequency of Hospital Visits
a	Male	40's	Leukemia	3–10 years	Every 1–3 months
b	Female	50's	Hereditary disorder	10 years or more	Every 1–2 weeks
c	Male	60's	Rheumatism	10 years or more	Every 1–3 months
d	Female	40's	Breast cancer	3–10 years	Every 1–3 months
e	Male	30's	Brain disorder	10 years or more	Every 1–3 months
f	Male	50's	Type 1 diabetes	10 years or more	Every 1–3 months
g	Female	40's	Sarcoidosis	10 years or more	Every 3–6 months
h	Female	50's	Systemic lupus erythematosus	10 years or more	Every 1–3 months
i	Male	30's	Embryonal carcinoma	10 years or more	No hospital visits
j	Female	30's	Endometrial cancer	10 years or more	Every 6–12 months

Table 2 Themes and Codes

Theme/Category	Code
Experience & acceptance of chronic conditions	
Before disease onset	Did not think about life and death Had good relationships with healthcare providers No awareness that they had a disease Patient communities were not needed Did not actively engage with healthcare and healthcare providers
Suffering and setbacks due to the disease	Experience of adverse effects from medical treatment Discontent with healthcare providers Suffered from a lack of information about the disease Became suspicious of the health care system Experience of disease onset and severity Suffered mental anguish due to the disease Difficulties in employment and social participation due to the disease Experienced medical malpractice
Impact caused by suffering and setbacks	Became more actively engaged with healthcare and healthcare providers Changed the view of their health Became motivated to contribute to society by their own experiences of disease Motivated to join the patient community Participated in the patient community
Features of medical SC	
Function of medical SC	A place where participants can dialogue with other participants as equals A place where people feel comfortable A place to meet and interact with other participants A place to gain new awareness and knowledge A place where people can use their experience of disease to make their lives meaningful. A place for mutual sharing and use of disease experience
Design of operation	Each session is a one-time even Attracts active and caring people People from any background can participate A wide range of thematic issues are discussed Held in a face-to-face setting Opportunities for speech are guaranteed Respect for the things they say Topic provided by guests
Changes as a result of participation	
Active attitude toward medical care	Become aware that they are on equal footing with healthcare providers Be understanding of what healthcare providers think Become more interactive with healthcare providers Become actively engaged in treatment
Changing values on health and medical care	Changing values about own health or medical care Trying to use their experience to contribute to society
Acceptance of own disease	Come to see it as a valuable experience Become more aware of their disease and its relationship to society Be able to talk to others about their disease Learn to deal with their own disease Become more aware of the value of being healthy.

Suffering and Setbacks Due to the Disease

The onset of the disease brought about diverse challenges, including adverse effects from medical treatments, discontent with healthcare providers, and a significant amount of mental anguish. For example, participant B, whose father also had

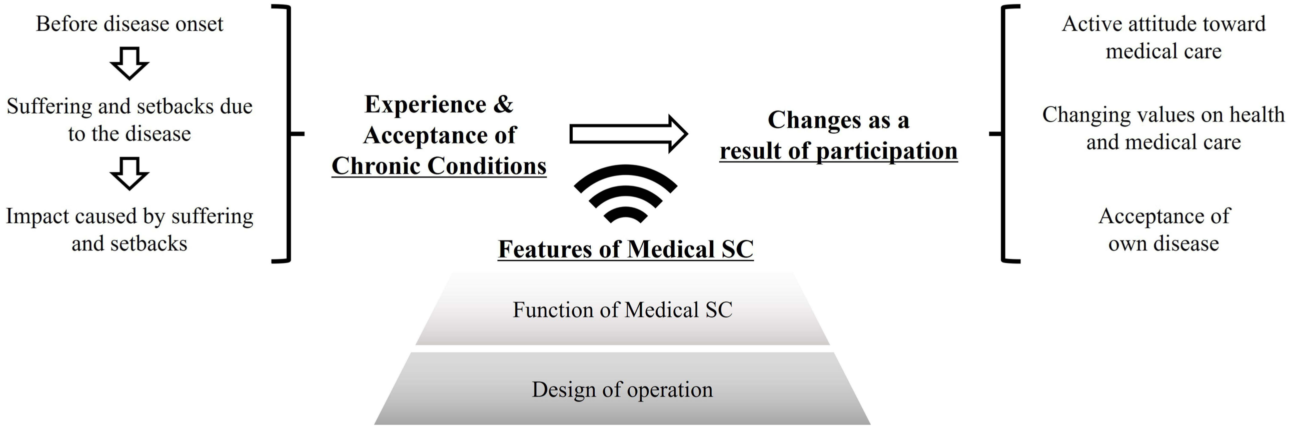

Figure 1 Structure between themes This structure shows that individuals with backgrounds described in "Experience & acceptance of chronic conditions" engage in a setting with multiple functions as shown in "Features of medical SC" and undergo changes as described in "Changes as a result of participation".

the same disease, described experiencing a mix of relief and an overwhelming focus on their disease after the diagnosis, which occupied a substantial part of their daily life, leading to emotional instability.

> At first, when I was just diagnosed, I felt somewhat relieved. But looking back, I realized I was mentally unstable at that time, engrossed with the disease. It occupied a large part of my life. I spent a lot of time thinking about the disease, and I remembered crying every morning, thinking about my father. My father had experienced significant difficulties, yet he went to his office job every day to support us. Recalling his struggles made me cry alone every morning. - Participant B (Code: Suffered mental anguish due to the disease)

Impact Caused by Suffering and Setbacks

The adversities and setbacks experienced due to the disease eventually led to a transformation in the participants' approach to their health and healthcare engagement. They became more proactive in seeking information, especially about their condition, and engaging with healthcare providers. This dynamic motivated them to become involved in patient communities such as medical SC. Participant E's account highlights this shift and underlines the recognition of the importance of being proactive in engaging with healthcare after encountering a health problem.

(Interviewer YO: So, you mentioned not asking medical professionals many questions in the past. Was it because you hesitated to ask them?)

> Up until I was 30, I did not really consider myself a patient. I thought, "It's not a big deal" and "I'm not struggling." However, after experiencing a neck issue, I started to feel that I needed to take care of myself more seriously. From that experience, I began to think, "Maybe I should voice out my concerns or ask questions to the medical professionals."- Participant E (Code: Became more actively engaged with healthcare and healthcare providers)

Features of Medical SC

This theme delves into the unique features and operational designs of the medical SC, which participants identified as significant contributors to their transformative experiences. The theme can be broadly segmented into two categories: the intrinsic function of the medical SC and its design of operation.

Function of Medical SC

Participants perceived the medical SC as a catalyst in altering their personal approach to health. They emphasized the functions of the medical SC that directly fostered changes in them, such as finding enrichment in their lives by sharing personal experiences and obtaining new insights and knowledge.

> Indeed, with different themes and speakers every time, it truly serves as a simple place of learning. - Participant A (Code: A place to gain new awareness and knowledge)

Furthermore, they valued the SC as a place where they felt warmly welcomed and safe, regardless of their health status, disability, or personal values. This environment fostered a sense of belonging and each participant felt fully accepted.

> Even if it's your first time attending, there's an atmosphere of welcome. It doesn't matter what kind of illness or disability you have; there's a certain homely aspect that accepts you. - Participant C (Code: A place where people feel comfortable)

Design of Operation

The structure and operation of the SC were crucial in shaping its function and ensuring its effectiveness. A notable aspect was the role of a skilled facilitator who made certain that every participant, regardless of how outspoken they were, had an equal chance to share their experiences and insights.

> There are various people, but everyone has the power to speak. Usually, in such workshops, those with louder voices tend to dominate, but there, thanks to the skilled facilitator, everyone gets a chance to speak. - Participant E (Code: A place to gain new awareness and knowledge)

The location of the SC also contributed to its appeal, drawing in a variety of motivated participants. Many of these individuals held prominent roles in society and had a clear passion for learning and personal growth.

> Being held in the city center, I've noticed that many of the participants are passionate. Quite a few holds high social positions, and there's a general atmosphere of individuals eager to learn and improve themselves. - Participant F (Code: Attracts active and caring people)

Changes as a Result of Participation

This theme focuses on the shifts in participants' attitudes and behaviors as a result of their involvement in the SC. These transformations manifest in a more proactive approach to medical care, a reshaped perspective on health and medical values, and a deeper acceptance and understanding of their own diseases. We will delve into the specifics of each category, drawing insights from the participants' narratives.

Active Attitude Toward Medical Care

In this category, participants demonstrated a proactive approach to their health. This includes actively engaging with healthcare providers, voicing their thoughts and feelings, and adhering to medication as prescribed. For instance, one participant stressed the importance of being prepared for medical consultations by noting down their opinions and compiling questions beforehand, as well as documenting side effects in their medication logs.

> For example, doctors can't always spend their time solely for the patients, so it's important for us, the patients, to write down our opinions and gather our questions in advance. Also, even now, I make it a point to note down any side effects in my medication record. - Participant J (Code: Become more interactive with healthcare providers)

Changing Values on Health and Medical Care

This category highlighted a shift in participants' overarching values concerning their health and medical care. There was a sentiment of wanting to leverage their disease experiences for societal benefit. One participant viewed their encounter with a rare disease not necessarily in a negative light but as a precious experience.

> Isn't it quite a valuable experience? It's not often that one gets to experience a rare disease. So, thinking it's a valuable experience, I want to utilize it. By being open about it, people who are going through similar struggles or those who want to hear about it approach me. - Participant G (Code: Trying to use their experience to contribute to society)

Acceptance of Own Disease

In this segment, participants illuminated their path of coming to terms with their personal medical challenges. They conveyed an emerging willingness to converse about their ailments with others, adopting strategies to manage their individual conditions, and cultivating a deeper understanding of the value of health. A prominent discussion was about the internal conflict some experienced regarding the decision to share their health struggles more openly.

> The biggest change for me is about whether to disclose my illness to the public or not. Until then, I always tried to hide my illness or disability. Now, I've come to think that having a disease isn't necessarily a negative thing and it's something anyone could experience. - Participant A (Code: Be able to talk to others about their disease)

Questionnaire

Demographic Data of Questionnaire Participants

The questionnaire recruited 30 participants and obtained 23 responses. The demographic data of these participants is shown in Table 3.

Table 3 Demographic Data of Respondents to the Questionnaire

		n=23	**%**
Gender	Male	10	43.5
	Female	13	56.5
Age	20's	1	4.3
	30's	4	17.4
	40's	5	21.7
	50's	7	30.4
	60's	5	21.7
	70's	1	4.3
Education	High school graduate	1	4.3
	Junior college graduate	1	4.3
	University graduate	15	65.2
	Graduate school graduate	6	26.1
Employment	Employed	16	69.6
	Not employed	4	17.4
	Other	3	13.0
Participation in patient communities except PS	Yes	22	95.7
	No	1	4.3
Disease (multiple answers allowed)	Cancer	5	16.7
	Hyperlipemia	2	6.7
	Skin diseases	2	6.7
	Other (kidney disease, mental illness, etc./only 1 case)	12	40.0
	N/A	9	30.0
Duration of the disease	Less than 1 month	0	0.0
	1–6 months	1	3.6
	6–12 months	0	0.0
	1–3 years	1	3.6
	3–10 years	4	14.3
	10 years or more	13	46.4
	N/A	9	32.1
Frequency of hospital visits	More than once every week	1	5.3
	Every 1–2 weeks	1	5.3
	Every 2–4 weeks	2	10.5
	Every 1–3 months	9	47.4
	Every 3–6 months	3	15.8
	Every 6–12 months	2	10.5
	Less than once every year	0	0.0
	No hospital visits	4	17.4

Patient Activation and Each Measure

The scores of each instrument and its domains are shown in Table 4. Positive correlations to PAM-10 are found for DRS, BRS overall, and the BRS subscales of "innate resilience", "optimism", "sociability" and "self-understanding." As for the original AHP scale, four items were removed due to observed ceiling/floor effects. Furthermore, a set of questions was used in the correlation analysis with the PAM10, which was confirmed to be 1 factor with 6 items by the maximum likelihood method and Promax rotation.

Discussion

Impact of Medical SC on PA

In the "Theme: Experience & acceptance of chronic conditions" section, participants before the onset of the disease expressed a passive attitude towards their health status. Through the external pressures of distress and setbacks caused by the disease onset, there are narratives of understanding their role in healthcare and, in some respondents, becoming actively engaged with healthcare providers in their treatment. Such narratives are equivalent to PAM classes 1–2. From "Category: active attitude towards medical care" in "Theme: Changes as a result of participation", many interviewees showed an active attitude towards their treatment and healthcare providers, and some participants reported concrete actions. These seem to be narratives that correspond to PAM classes 2–3. In addition, the PAM-10 class in the questionnaire is equivalent to 2–3, which

Table 4 Summary of Scales and Correlation Analysis with Patient Activation Measure (n=23)

Instruments	**Average/Min-Max (SD)**	**Cronbach α**	**Pearson's r**
PAM-10 Score	53.91/0–100 (9.91)	0.80	
PAM-10 Class	2.26/1–4 (0.75)		
Community supportive functions scale (CSF)	46.17 / 17–68 (9.93)	0.91	0.15
A place to communicate as a healthy person	16.96 / 7–28 (4.49)	0.76	0.07
A place to have help from others	11.13 / 4–16 (2.77)	0.84	0.21
A place to learn about the disease	8.22 / 3–12 (2.19)	0.63	0.16
A place to have help from others	9.87 / 3–12 (1.58)	0.66	0.15
Sense of community index (SCI)	43.83 / 0–72 (12.21)	0.91	0.16
Integration and fulfillment of needs	11.96 / 0–18 (3.90)	0.89	0.23
Membership	10.78 / 0–18 (3.91)	0.76	0.22
Influence	10.35 / 0–18 (2.82)	0.46	0.21[a]
Shared emotional connection	10.74 / 0–18 (3.33)	0.76	−0.06
Generalized self-efficacy scale (GSE)	75.52 / 23–115 (13.22)	0.86	0.36
Bidimensional resilience scale (BRS)	73.17 / 21–105 (12.05)	0.91	0.53**
Innate resilience	40.48 / 12–60 (7.28)	0.85	0.57**
Optimism	11.22 / 3–15 (2.19)	0.67	0.56**
Control	9.65 / 3–15 (2.01)	0.47	0.4
Sociability	9.48 / 3–15 (2.68)	0.86	0.47**
Vitality	10.13 / 3–15 (2.70)	0.82	0.31
Acquired resilience	32.70 / 9–45 (5.58)	0.84	0.41
Attempting to solve a problem	11.35 / 3–15 (2.27)	0.70	0.26
Self-understanding	10.83 / 3–15 (2.04)	0.57	0.45*
Understanding others	10.52 / 3–15 (2.43)	0.86	0.32
European health literacy survey questionnaire (HLS-EU-Q16)	44.91 / 16–54 (6.89)	0.84	0.29
Health care	18.91 / 7–28 (3.74)	0.79	0.28
Disease prevention	14.48 / 5–20 (2.35)	0.52	0.24
Health promotion	11.52 / 4–16 (2.29)	0.73	−0.05
Decision regret scale (DRS)	25.43 / 0–100 (17.45)	0.85	−0.43*
Attitudes toward healthcare providers scale (AHP)	22.48 / 6–30 (4.61)	0.90	0.16

Notes: [a]Spearman's ρ, *p<0.05, **p<0.01.
Abbreviations: SD, standard deviation; PAM, Patient Activation Measure.

means that the PA of the medical SC participants is in class 2–3. Although not directly comparable, the PAM scores of the participants in this study who participated in the medical SC were significantly higher than the PAM-13 scores measured in outpatients with type 2 diabetes in Japan ($t = 3.14$, $p = 0.002$).[22] These findings indicate that participation in medical SC after the onset of disease could promote improvement from PA class 1–2 to 2–3.

The questionnaire also showed a weak negative correlation ($r = -0.43$, $p = 0.04$) between PAM and DRS. This may suggest that the higher the PA, the higher the quality of therapeutic decision-making. A similar suggestion was made in a previous study[4] and considering that SC participation improves PA as mentioned above, it is considered that medical SC participation improves PA, which in turn promotes shared decision-making (SDM) and improves the quality of SDM.

Structures Causing Change

Figure 1 shows how participants' PA changes appear to be structured. This structure means that people with backgrounds as shown in "Experience & acceptance of chronic conditions" participate in a place with multiple functions as shown in "Features of medical SC" and make changes as described in "Changes as a result of participation." This structure will be explored in more detail in connection with the questionnaire.

Looking at the relationship between PA and resilience, there is a significant correlation between the PAM and the subscale "self-understanding" of the BRS. This scale measures resilience by differentiating between innate and acquired factors. In the interview, "Theme: changes as a result of participation" and "Category: acceptance of own disease" include narratives about accepting their disease and their situation and making their lives more meaningful. Previous research on medical SC has also shown that participation in medical SC promotes "self-consideration."[9] These findings suggest that the deeper self-understanding of participants resulting from medical SC may improve PA.

Although the positive correlation is weak, the relationship between PAM and SCI in the questionnaire is $0.20 \leq r$, except in the domain of "shared emotional connection". This shows that while membership and interaction between participants influence PA improvement, the mentality of the participants is that they recognize each other as independent individuals and respect others. This is also supported by the interviews, which include participants' narratives about respecting each other's comments.

Limitations

The cross-sectional nature of our data collection, both in the questionnaire and interview, constrains our ability to definitively conclude that the medical SC influenced participants' PA improvement. Notably, over half of our questionnaire respondents have been navigating their illness for an extended duration, exceeding three years. This raises the possibility that observed changes in PA might be attributed to the natural progression of time rather than the influence of the medical SC. Indeed, a related study focusing on dialysis patients indicated that a certain proportion of them witnessed either an increase or decrease in their PAM levels within the first four months of initiating dialysis.[23] This observation underscores the need to consider the temporal evolution of disease and its potential impact on participants' perceptions and experiences. Nonetheless, our discussion about PA improvement is grounded in changes perceived by respondents to have occurred along a timeline due to the influence of the medical SC. It would be helpful in a future study to quantitatively evaluate the PAM score dynamics before and after SC engagement.

The study's results might bear the imprints of the specific backgrounds and characteristic inclinations of our participants, as the recruitment was limited to a single community. For instance, the BRS unveiled correlations with inherent traits like "optimism" and "sociability." Such findings may imply only those who are intrinsically optimistic and sociable are likely to derive positive outcomes from the medical SC. Alternatively, the recruitment strategy, which favored individuals with consistent attendance, might have favored participants with certain predispositions, such as optimism. This could have unintentionally sidelined those less predisposed to attend, possibly due to their inherent traits or the nature of their disease progression.

Another limitation of this study is the small number of participants. According to Insignia Health, at least 75 samples are recommended for use with PAM, whereas in this study only 23 samples were collected. Although the questionnaire was used in this study to reinforce the results of the interview, future surveys need to include more samples.

Given these nuances, prospective research should integrate longitudinal data collection, extend the communities under study, and perhaps employ stratified sampling techniques to take account of variations in disease duration and individual temperaments.

Theoretical Implications

According to prior research, the changes observed in participants of Science Cafés have been interpreted using Mezirow's framework of transformative learning.[9] Transformative learning is defined as a process in which individuals critically reflect on their own experiences and values, subsequently forming new perspectives and understandings.[24] As mentioned previously, our research also suggests that dialogues in the Science Café format of medical SC prompt participants to self-reflect. This self-reflection acts as a catalyst in promoting a transformation in perspectives, which includes changes in PA.

Earlier studies supported the hypothesis that the operations within the framework of Science Cafés provide a platform for open dialogue, and this environment fosters transformative learning. However, these studies did not specify how particular designs and operations create such an environment. Furthermore, the analysis in these prior studies was limited to immediate post-SC implementation, leaving the long-term behavioral and cognitive changes influenced by such experiences largely unexplored.[9]

Our research contributes by addressing these gaps. Specifically, the operational design of medical SC cultivates open and autonomous dialogues among individuals with diverse values. We believe that this facilitates self-reflection based on the framework of transformative learning, prompting a shift in perspectives, including changes in PA. We also posit that this transformation leads to tangible actions, such as individuals managing their own medical treatments.

Practice Implications

The study highlights the potential of the medical SC as a tool to promote patient engagement in self-management. By attending a medical SC, individuals can gain insights into various health topics, broadening their understanding and encouraging proactive involvement in their healthcare journey. These sessions are not tailored to specific diseases but offer general health knowledge beneficial for self-management. Engaging with healthcare providers and other participants in this setting fosters collaboration and mutual learning. To maximize the benefits, it is important to create inclusive environments that cater to diverse groups of people. This can be achieved by creating a supportive environment where individuals can share their experiences, learn from others, and feel heard. The study highlights the potential benefits of using the medical Science Café as a strategy for healthcare providers to increase PA and improve health outcomes. The utilization of a medical Science Café in this supportive environment by healthcare providers can improve patient activation (PA) and enhance health outcomes.

Conclusion

From the interviews, three themes were generated to describe the structure that influences participants in a medical SC: "Experience & acceptance of chronic conditions", "Features of medical SC" and "Changes as a result of participation." The relationships among these themes can be interpreted as "changes as a result of participation", whereby participants, described as "Experience & acceptance of chronic conditions", are influenced by the functions of the healthcare SC as seen in "Features of medical SC."

The narratives corresponding to PAM classes 1–2 in "Experience & acceptance of chronic conditions" changed to PAM classes 2–3 as described in "Changes as a result of participation." This suggests that participation in a medical SC could improve PA by empowering those who have become actively involved in their healthcare.

Data Sharing Statement

The interview and questionnaire data used to support the findings of this study are available from the corresponding author upon request.

Ethics Approval and Informed Consent

Approval for the study was obtained from the Research Ethics Review Committee, Keio University Faculty of Pharmacy (approval number 210708-4). Written or digitally informed consent was obtained from all study participants.

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Author Contributions

Conceptualization: YO, HK, NS, WO, SH. Methodology: YO, HK, WO, SH. Resources: NS, SH. Investigation: YO, KH. Formal analysis: YO, KH. Data curation: YO. Writing – original draft preparation: YO. Writing – review and editing: YO, KH, NS, WO, SH. Visualization: YO. Funding acquisition: SH. Project administration: SH. Supervision: SH.All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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