

RESEARCH COMMUNICATION

A Qualitative Study of Japanese Patients' Perspectives on Post-treatment Care for Gynecological Cancer

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Abstract

The perspectives of cancer patients are important for designing a medically and economically effective follow-up program to help in the rapid recovery of patients. However, research focusing on the perspectives of Japanese gynecological cancer patients on follow-up programs is extremely scarce. In this study, we explored the perspectives and expectations of Japanese gynecological cancer patients with regard to post-treatment follow-up. Twenty-eight patients recruited through a gynecological cancer support group were included in focus groups 1–10 years post-treatment. Participants' accounts related to their perspectives on follow-up were coded and grouped into themes according to commonalities and differences. Seven themes emerged as follows: (1) living with uncertainty, (2) monitoring recurrence, (3) test content and frequency, (4) coping with “another illness,” (5) provider communication and attitude, (6) holistic care, and (7) compromising with the reality of changed body. While these Japanese gynecological patients regarded follow-up as an opportunity for reassurance, they also wanted treatment for adverse effects and the opportunity to discuss their concerns. On the basis of the study findings, we conclude that during follow-up after cancer treatment, Japanese gynecological cancer patients not only prioritize recurrence management of cancer but also place a significant amount of importance on the management of symptoms and doctor-patient communication. However, these expectations for communication and care are often unmet. Thus, there is a need to fulfill the gap between the current follow-up programs and patients' expectations by reviewing and changing the hospital's policy that mainly focuses on the detection of recurrent diseases.

Keywords: Cancer - oncology - gynecology - follow-up - patients' perspective - Japan

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Introduction

Gynecological cancer patient follow-up typically focuses on detection of early disease recurrence and management of physical and psychological adverse effects (Colombo et al., 2010; Haie-Meder et al., 2010; Plataniotis et al., 2010). However, the effectiveness of existing follow-up programs for detecting early recurrence and improving survival is debatable (Kew et al., 2005; Zola et al., 2007; Elit et al., 2009). Additionally, the need of gynecological cancer survivors for information and care is often neglected (Pennery and Mallet, 2000; Pun Wong and Chow, 2002).

Designing an effective follow-up program that incorporates the perspectives of cancer patients is important. Several studies conducted to date have explored this issue. For instance, a qualitative study by Bradley et al. (1999) revealed that the main concerns of women desiring continued follow-up are detection of cancer recurrence and specialists' reassurance (Bradley et al., 1999). In a subsequent quantitative study, the same research group

reported that women desiring continued follow-up had significantly higher anxiety levels (Bradley et al., 2000). Survey studies by Kew et al. (2007, 2009) also showed that gynecological cancer patients ranked recurrence detection as the main reason for follow-up (Kew et al., 2007; Kew et al., 2009). Furthermore, Lydon et al. (2009) conducted focus group interviews of six ovarian cancer patients, which also revealed that patients considered clinical examination for disease recurrence important (Lydon et al., 2009).

Collectively, these studies affirm that recurrence detection is the primary concern of gynecological cancer patients during follow-up. However, to date, there has been insufficient information gathered on patients' perspectives on follow-ups, particularly in relation to resuming their daily lives. Furthermore, only a few studies have qualitatively explored the perspectives of gynecological cancer patients (Lewis et al., 2009). Moreover, related research focusing on the assessment of Japanese gynecological cancer patients is extremely scarce.

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Literature on gynecological cancer survivorship and survivors' supportive care needs pointed out that patients have physical, psychosocial, and relational concerns and need information and moral support in the post-treatment period (Auchincloss, 1995; Miller et al., 2003; Lockwood-Rayermann, 2006; Wray et al., 2007; Walton et al., 2010). However, it is unclear how gynecological patients' expectations are related to their follow-up visits and consultations with gynecologists.

In Japan, post-treatment gynecological cancer patients typically enter a follow-up program in the same hospital department that offered the treatment. The program usually consists of various examinations and tests to monitor clinical parameters, as well as a consultation provided by a gynecologist specializing in gynecological oncology. Approximately 35,000 Japanese women are diagnosed with cervical, uterine, or ovarian cancers each year; thus, the age-standardized rates of gynecological cancers are the second highest among cancers afflicting Japanese women (Matsuda et al., 2011). Therefore, it is especially important to understand how Japanese gynecological patients experience follow-ups and post-treatment care.

Accordingly, this study was performed to qualitatively explore the perceptions and expectations of Japanese gynecological cancer patients during post-treatment follow-up.

Materials and Methods

Research design

We used qualitative research methodology to capture the perspectives of study participants (Maxwell, 2005) and to reveal the beliefs and values underlying individual health behavior (Curry et al., 2009). Through focus groups, we explored a variety of perspectives in small group discussions (Kitzinger, 1995; Curry et al., 2009).

The research protocol was approved by the ethical committee of the Graduate School of Medicine of Hokkaido University.

Participant recruitment

Gynecological cancer patients who were on 1–10 years post-treatment without recurrence were recruited. To collect a range of perspectives from patients attending different hospitals, invitations were enclosed with a newsletter sent to approximately 400 members of a Japanese gynecological cancer support group. This support group is a locally based patient group founded and organized by gynecological cancer patients treated at a variety of hospitals across the region and a small number of supporters. The group is designed to help members by offering regular free-discussion sessions to share their thoughts and experiences.

The invitations included the study details with the dates and places of the planned focus groups. By the established due date for inquiries, 32 women showed interest in partaking in the study. Among these women, two breast cancer patients and one cervical cancer patient <1 year post-treatment were excluded. Study details were explained to all enrolled participants, and written consent

Table 1. Interview Topics

What do you think about follow-up?
What has your follow-up been like post-treatment?
Why do you attend follow-up?
If you have a problem after treatment, is it solved during follow-up?
Are you satisfied with follow-up?
What do you think about your doctor?
What kind of care do you want for follow-up?

Table 2. Demographic Characteristics of the Study Participants (n = 28)

Characteristics	N
Age (years)	
40–49	7
50–59	7
60–69	13
70–79	
Cancer site	
Cervix	9
Endometrium	11
Ovary	7
Vulva	1
Marital status	
Married	23
Divorced/widowed/separated	4
Never married	1
Education	
Less than high school	2
High school	17
College	9
Employment status	
Employed full-time	2
Employed part-time	11
Self employed	1
Home duties	11
Unemployed	3
Time since completion of treatment (years)	
1–2	5
2–3	3
3–4	3
4–5	6
5–6	1
6–7	4
7–8	3
8–9	0
9–10	3
Frequency of follow-up visits (months)	
2 or less	5
3–4	11
6	10
12	2
Treatment received	
Surgery alone	12
Surgery and chemotherapy	15
Surgery, chemotherapy, and radiation therapy	1

was obtained from them.

Data collection

Focus groups were adopted to promote self-disclosure and active discussion through participants' interaction (Kitzinger, 1995). Four focus groups (6–8 participants each) were conducted at local community centers in November–December 2009. Using a topic guide (Table

1), the participants were asked to explain their perceived purpose, experience, and expectation of follow-up. All interviews were conducted in Japanese. The principal author (SO) of this study conducted all patient interviews. Participants received compensation for their time in the form of shopping coupons (3,000 yen) for their time and conveyance. A nurse trained in data collection assisted the principal author to conduct interviews of the focus group and took notes of interactions and non-verbal communication during the discussions.

Each interview (60–90 min) was audiotaped by the principal author and transcribed by a professional transcriber. The interviewer subsequently checked the transcripts against the recording. One participant requested that her data be withheld; thus, the data of 28 women were used in the final analysis.

Table 2 shows the profiles of the enrolled study participants. Specifically, 17 participants were less than 5 years of completing cancer treatment and 11 were within 5–10 years of completion. The participants were aged 41–71 years (median, 59 years) and comprised a proper mix of subjects with three major gynecological malignancies (cervical, uterus, and ovarian). This patient range helped us to explore diversity in the follow-up experiences of gynecological cancer survivors.

Data analysis

Patient statements were coded and grouped by the principal author into themes according to their commonalities and differences using thematic analysis (King and Horrocks, 2010). This was sequentially done for all the groups, and the themes were revised, if necessary, after each group's statements were coded. The codes, themes, and theme-theme relationships were compared using the constant comparative analysis (Corbin and Strauss, 2008). Emergent codes and themes were altered if necessary after discussion with team members (KK, TT, and MH) and with supervisors experienced in qualitative data analysis (HK and MM) for triangulation (Patton, 1999). This process was continued until no new codes and themes emerged.

Results

Seven themes emerged from the analysis of patient statements: (1) living with uncertainty, (2) monitoring recurrence, (3) test content and frequency, (4) coping with "another illness," (5) provider communication and attitude, (6) holistic care, and (7) compromising with the reality of changed body. Themes (1) and (7) reflected women's daily-life-based and follow-up-related perceptions; the other five themes dealt only with follow-up-related perceptions and expectations.

Living with uncertainty

Uncertainty was evident among the participants. In particular, some women worried about recurrence, whereas others worried about prolonged symptoms. Moreover, signs of ill health were linked to possible adverse effects, according to the perceptions of some participants. Furthermore, some patients responded that

completion of treatment did not necessarily mean recovery. Therefore, they considered the future as unforeseeable:

"I am worried about recurrence. Although I have recovered, I wonder what will happen if my cancer recurs." [participant #18]

"Four months have elapsed (since lymphedema development), and now I am worried that something else might occur. When I have an upset stomach, I wonder if I've now got an intestinal disorder because some women have reported such disorders after gynecological surgery." [participant #29]

Monitoring recurrence

Most participants considered the aim of follow-up to be detection of disease recurrence. Others considered follow-up as an opportunity for reassurance and to confirm the absence of recurrence signs:

"I visit the hospital every three months because of the possibility of recurrence. I want it to be detected early." [participant #20]

"I don't have any particular problems. During every visit, I feel relieved knowing that everything is all right." [participant #15]

Participants' opinions on recurrence management were divided into two types. That is, they attend follow-up either to detect recurrence or to gain reassurance that they are recurrence-free. However, based on their remarks, it could not be determined what factors prompted the participants to be either recurrence- or reassurance-oriented. It can be assumed that their understanding of follow-up was dependent on the information they received from their physicians about their recurrence possibility. However, discussions revealed that participants sometimes made their own judgments, as one ovarian cancer patient stated:

"My doctor was concerned about my cancer and advised me to visit the hospital monthly. After three years, the follow-up interval was changed to three months. But I think I am fine and the cancer will not recur." [participant #16]

Most participants received their follow-up results by post. Although participants claimed to accept the notification manner and delay, the waiting period was a burden on their emotional state. For most participants, the period after treatment eased the burden of waiting, but anxiety existed among some participants who had passed the 5-year mark:

"Three months later, before the next follow-up, I felt depressed. I was worried about what I would do if my doctor gave me a bad result." [#28, 8 years post-treatment] "I feel nervous for a week until the result arrives. But I think I am fine about the disease now." [participant #11, 7 years post-treatment]

Test content and frequency

Test content and frequency, as well as participant concerns, were closely related to recurrence monitoring, especially the test significance and follow-up schedule.

Test significance

During follow-up, participants typically undergo blood tests, pelvic examinations, X-ray examinations, ultrasound

examination, computed tomography scans, magnetic resonance imaging, and positron emission tomography. On the basis of their responses in this study, the participants wanted their doctors to explain the importance of the tests and the results in detail. Importance of test especially becomes an issue when women undergo uncomfortable tests or wonder whether they will feel reassured. Many participants were embarrassed by pelvic examinations and were frustrated about their necessity. In contrast, the majority of participants considered a blood-tumor-marker level test to be important. One woman who had undergone a pelvic examination said:

“My doctor does not check tumor marker levels and only performs a pelvic examination. I asked him ‘How long will it continue?’ because of the discomfort. He replied ‘Checking by sight is best.’ The tests make me tense and stiff. Regarding tumor marker tests, he said ‘If you insist, I can order them.’ I said ‘If they are not needed, that is fine.’” [participant #10]

Presentation of tumor marker test results to patients varied from presentation of numerical levels without interpretation to doctor assurance alone. Participants expressed a desire to understand what the resultant levels meant:

“For me, tumor marker levels are an index of reassurance. If they are normal, I feel I can continue working.” [participant #30]

“I ask my doctor to print tumor marker test results. The figures reassure me. I want to understand whether the result is high, low, or normal.” [participant #20]

Follow-up schedule

Follow-up intervals increase (i.e., more time between visits) with the elapsed time from treatment. The participants in this study accepted and followed their doctors’ decisions about follow-up schedules; however, changes in schedules sometimes became stressors. Some women stated that they felt anxious that something was wrong during prolonged intervals:

“When the interval increased by two months, it felt long. I felt lonely rather than worried, and the thought of a bad result flashed through my mind. When the interval was extended to three months, I was worried that something was wrong.” [participant #2]

In contrast, other participants preferred prolonged intervals or discharge. One participant shared her experience of requesting discharge, but her doctor did not approve her request:

“On visiting my doctor, I said, ‘I feel fine about my cancer. Should I continue follow-up?’ He said, ‘I want you to come for a minimum of 10 years.’” [participant #11] Of note, the desire for schedule changes and discharge was associated with payment burden for some. One woman said:

“I went to the hospital monthly and had to pay more than \$80 per visit. Because my family was struggling financially, it was expensive. When the interval increased, I felt my life became easier.” [participant #1]

Coping with “another illness”

Throughout focus group discussions, there was much

talk about various adverse effects of treatment, including urinary discomfort, lymphedema, and numbness in the fingers and toes. These physical problems were regarded as “another illness,” which weighed heavily on participants struggling to recover. The participants often considered the symptoms more serious than the actual cancer. One woman with lymphedema said:

“Now, I am more distressed than before. I used catheters for six months knowing the possibility of urinary discomfort. The symptom disappeared. Then lymphedema occurred, and sometimes I feel terrible while climbing stairs.” [participant #9]

Participants with prolonged symptoms considered follow-up visits as opportunities to consult with doctors. However, sometimes adverse effects went untreated, causing symptom exacerbations. When women felt they were not receiving enough follow-up care, their symptoms were considered treatment legacies. Some participants struggled with their symptoms, while others had abandoned their search for treatment:

“I told my doctor that my toes felt numb. First, I thought that it was an aftereffect of the anesthesia, but the doctor said it was due to chemotherapy. He said it would disappear soon; but as time elapsed, he said it would take three years—then four years. I wondered whether he did not have any empathy for me or did not know how to.” [participant #2]

“I was told that my leg might swell, but I didn’t think it would be as horrible. Three months after surgery, my leg became terribly swollen and I had a high fever, but the doctors did not know the reason. My doctor said I should feel lucky to be alive despite swelling of my leg.... I thought I wouldn’t have had my lymph nodes removed if I had known that this would be so terrible. But it was too late.” [participant #13]

Provider communication and attitude

The majority of participants wanted to establish rapport with their doctors and hoped for reassurance and discussion regarding their concerns. They expressed gratitude when doctors encouraged them to ask questions, answered questions willingly, and showed concern regarding recovery. Moreover, some participants spoke about the importance of doctors’ opinions and regarded them as a blessing:

“My doctor answers any question I ask, even when I ask about newspaper articles or television programs featuring cancer. When one of my blood tests was abnormal, he explained it in detail and asked me not to worry. I am so grateful to him.” [participant #1]

“I feel annoyed when the doctor looks unenthusiastic during consultation, but I feel good when he says words of comfort. My friends cannot pacify me as much as doctors. I think that it is enough for me to attend follow-up every three months.” [participant #12]

In general, participants wanted to maintain continuous consultations with their doctors. When changing gynecologists, women felt disappointed; later, they made efforts to build a relationship with the new doctor. One woman discussed her complex feelings while adapting:

“I trusted the doctor who treated my cancer; I missed

him when he was gone. With the new doctor, I found it difficult to communicate. Then the doctor changed again. The present doctor seems so busy that sometimes I leave without even sitting. I want more time to talk with the doctor, so I thought about changing my physician.” [participant #22]

In contrast, study participants expressed frustration about hasty, inadequately informative consultations and non-communicative doctors. They also vocalized their disappointments about doctors' indifference regarding adverse effects:

“My doctor looks like a difficult person. But I have plenty of questions to ask and want to communicate with him. What will happen next? When can I say I have completely recovered? I want to ask him such things, but I can't. I say only 'yes' in consultations.” [participant #29]
“I want more consultation time. The atmosphere does not permit you that. It seems like the moment you sit before the doctor, it is over. I really want to sit and talk patiently.” [participant #21]

Because of their bad experiences and changing of doctors, some women said they did not have high expectations of their doctors and needed only test results during consultation:

“My doctor said he did not know about [the cause of my leg swelling]. He thinks it is not a big deal and said something like living with leg swelling is better than dying. So I searched for another clinic. I now visit for follow-up to check tumor marker levels and don't ask anything about my leg.” [participant #13]

Holistic care

Study participants also talked about care, particularly holistic care, after cancer treatment. Those with adverse effects expressed deep frustration over the lack of care other than assessment of the recurrence. The participants were particularly frustrated with the doctors' attitude toward their prolonged symptoms. Discussions focused on adverse effects, mostly lymphedema and urinary discomfort, but also on fatigue and sexual activity:

“Hospital-provided documents indicated that there was the possibility of developing lymphedema or urinary discomfort. If so, care should be taken. They know surgery can cause such problems, so I want the hospital to provide adequate aftercare.” [participant #7]

“Post-treatment problems were different from what I read in hospital-provided literature. It said you can resume living a normal life, including sexual activity, but in fact my vulva shrunk. I wish there were treatments for such problems. It is really difficult to ask such things, especially in hurried consultations.” [participant #27]

Participants expected follow-up programs to be opportunities for receiving, not only recurrence management, but also holistic care. Participants whose doctors took notice of such data, even if it was unrelated to gynecological cancer, appreciated such solicitude:

“I have kidney disease, high blood pressure, and neurological illnesses. My doctor keeps monitoring these data on electronic medical records and advises me. He is taking care of everything.” [participant #1]

Participants expressed mixed feelings about being

referred to other departments or clinics for their symptoms. Some felt rejected by gynecologists who referred them to other specialists, while others accepted that it is unrealistic to expect gynecologists to treat all post-treatment symptoms. Some women expressed a desire for the hospital to provide total care:

“When I complain about my symptoms to my doctor, he usually says, 'We are not in charge of that symptom.' Each time this happens I am disappointed and feel like he does not listen. I told him about the symptoms because they occurred after the surgery and thought he would know about them, but the doctor advised me to visit other doctors. I wish there were more explanations.” [participant #21]

“I wish there was a care unit where you could receive care and advice if you suffer from adverse effects, so that you don't need to worry alone without knowing what to do. I would like to have such a clinic in the same hospital, because it would be the best solution to all my problems during follow-up.” [participant #2]

Compromising with the reality of changed body

With regard to activities of daily living, participants faced the reality of an aching body that had changed after cancer treatment. They were struggling to return to normal life while seeking a way to reconcile themselves with their weakened body:

“I lost strength after treatment. I stumble even when I walk on level surfaces. My muscles weakened and I could not raise my feet. So I went for a walk everyday with a wig and a hat and built up my strength. Now I have resumed working, but I cannot work full-time because I feel exhausted. I wonder where this fatigue comes from.” [participant #30]

“I work as a care worker at a nursing home. My left leg swells because I keep standing for a long time. So I go with my leg swathed with bandages, but it is inconvenient. I know I have to accept my condition since I have survived, but I want a way to resolve the inconvenience in my everyday life.” [participant #13]

According to discussions, symptom control from adverse effects was crucial for participants to resume work and do housework. Interestingly, although follow-up was regarded as an opportunity to find solutions for symptom control, participants were not totally dependent on medical interventions. They mentioned asking doctors to stop drug prescriptions for treating urinary discomfort and to provide menopausal symptom management without using prescribed drugs. They also spoke of visiting clinics offering better treatments. Furthermore, they were trying to incorporate need-based medical care and self-care into their lives:

“I was on self-catheterization post-surgery. Now I can manage without a catheter but sometimes have incontinence. My doctor prescribed drugs for it, but since they are expensive, I said, 'I can manage by myself' and take care of myself by visiting the bathroom frequently.” [participant #19]

“I asked for traditional herbal medicines to control menopausal symptoms at follow-ups, but there were not many options. So I visited a doctor who has knowledge

Discussion

Consistent with previous studies, this study reinforced the finding that patients regard recurrence management as a prime aspect of follow-up (Bradley et al., 1999; Kew et al., 2007; Kew et al., 2009; Lydon et al., 2009). Data from this study revealed that examination results typically provide patient reassurance, although some patients were apprehensive on the days before their visits and while waiting for the results.

Moreover, it was found that test content and frequency was important for reassuring women, which suggests the importance of providing detailed information about the importance of various tests and result interpretation.

This study also identified two important themes that have not received much emphasis in the existing literature on gynecological cancer patients' follow-up perspectives: coping with “another illness” and holistic care. Participants mentioned recurrence detection or reassurance of no recurrence as reasons for attending follow-up. However, women with neurotoxicity, lymphedema, urinary discomfort, and menopausal symptoms expected further care. They requested not only reassurance but also solid information on diagnosis and treatment during follow-up. A considerable percentage of gynecological cancer patients suffer from physical problems that do not recede with time (Wenzel et al., 2002; Beesley et al., 2007; Skjeldestad and Rannestad, 2009); chemotherapy recipients or lymphedema-diagnosed patients often have deep unmet needs (Beesley et al., 2008). Consequently, when patients have their next point of contact with their attending gynecologists, it is not surprising that they have high expectations for the treatment of adverse effects. Similar expectations have been shown in studies on other cancer patients (Pun Wong et al., 2002; Absolom et al., 2009).

This study also suggested the influence of patient-doctor communication on the patients' reassurance and ability to cope with adverse effects. In the absence of any obvious symptoms of recurrence, consultations with gynecologists confirmed the results of follow-up medical checkups. Concerns in the content and frequency of tests were often left unresolved when information was not given during consultation. Furthermore, consultation was an important opportunity for participants to discuss with their physicians the options for relieving their symptoms. During consultations, some participants gained information and support by actively involving gynecologists; however, most participants hesitated to ask questions or express concerns. Participants satisfied with follow-up consultations were those receiving empathetic responses and sufficient information.

The above-mentioned trend may result partly from the tendency of Japanese patients to wait for physicians' cues before expressing their views (Okamoto, 2007). Studies focusing on the communication involved in Japanese cancer consultations also revealed the importance of open-ended questions (Ishikawa et al., 2002), and biomedical

information-giving and counseling (Takayama and Yamazaki, 2004) to achieve patient satisfaction and self-perceived participation. We found similar results. Patients dissatisfied with communication with their doctors were distressed. This finding suggests the importance of the physician's communication style to patients' psychological health during follow-up consultation, as shown in another study on cancer consultation in Japan (Takayama et al., 2001).

Finally, this study highlights post-treatment gynecology cancer patients' follow-up perspectives and the uncertainty in their daily lives, causing continued worries about the future. Follow-up starts when patients struggle to return to their daily lives and face the reality of their treatment-affected bodies. Thus, follow-up is expected to provide opportunities for reassurance, clues and measures for reducing uncertainty, and reconciliation with reality. This is in line with a previous study that pointed out that the post-treatment period was perceived as a “further stage of illness, not a ‘return to good health’” (Bradley et al., 1999), because patients often struggle to recover during this period. This may be a reason why patients expect holistic care during follow-up. It is important to note that their expectation for adverse-effect care represents patients' desires for their body and their life to recover and reconcile with their daily lives. For patients, follow-up visits serve as milestones on the road to recovery and reconciliation. Indeed, grasping what the post-treatment period is like for patients provides physicians a deep understanding of their perceptions and expectations.

This study has several limitations. First, since participants were recruited through a cancer support group, opinions from patients reluctant or unable to participate in cancer support groups (for instance, due to psychological problems) were not obtained. Second, we did not explore other follow-up models because alternative models in gynecological cancer are rarely explored in Japan, and the sample population had only experience of consultant-led follow-up. Lastly, there may be a volunteer bias because of the low response rate.

In conclusion, care for their post-treatment symptoms and doctor-patient communication are just as important as recurrence management during follow-up from the perspectives of Japanese gynecological cancer patients. Detailed information about clinical tests, including interpretation of their results and the survival benefits of follow-up, is important because lack of this information can increase anxiety in patients. Even when patients did not ask questions to their physicians during consultation, they wished for supply of information and care. The merits of care provision provided by multidisciplinary specialist teams should be explored, including whether such services would be acceptable for gynecological cancer patient follow-up. Role-sharing by medical professionals should be a focus of future investigations. Future research is also necessary to provide detailed insight into communication issues during follow-up and to explore follow-up programs that can help patients recover. Follow-up programs should be integrated in light of how to best support patients seeking rapid recovery.

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