

Evaluation of A Novel Information-Sharing Instrument for Home-Based Palliative Care: A Feasibility Study

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Kouichi Tanabe, PhD¹, Koichiro Sawada, MD², Masanari Shimada, MD², Shinichi Kadoya, MD, PhD², Naoki Endo, MD², Kaname Ishiguro, MD, PhD², Rumi Takashima, BS², Yoko Amemiya, BS², Yasunaga Fujikawa, BS², Tomoaki Ikezaki, MS², Miyako Takeuchi, BS², Hidenori Kitazawa, PhD², Hiroyuki Iida, MD, PhD², Shiro Koseki, MD³, Tatsuya Morita, MD⁴, Koji Sasaki, BS⁵, Tatsuhiko Kashii, MD, PhD¹, and Nozomu Murakami, MD, PhD⁶

Abstract

Aim: To examine the feasibility and usefulness of a novel region-based pathway: the Regional Referral Clinical Pathway for Home-Based Palliative Care. **Method:** This was a feasibility study to evaluate the frequency of variances and the perceived usefulness of pathway using in-depth interviews. All patients with cancer referred to the palliative care team between 2011 and 2013 and received home care services were enrolled. **Result:** A total of 44 patients were analyzed, and pathway was completed in all the patients. The target outcome was achieved in 61.4% while some variances occurred in 54.5%. Nine categories were identified as the usefulness of the pathway, such as reviewing and sharing information and promoting communication, education, motivation, and relationships. **Conclusion:** This novel pathway is feasible and seems to be useful.

Keywords

patient-held records, information sharing, regional clinical referral pathway, home-based palliative care, multidisciplinary team care, daily record production

Introduction

When organizing a multidisciplinary team to provide patients with home-based palliative care, it is important to enable information sharing among the health care workers involved because home-based palliative care is typically provided by medical staff from different institutions across the region (eg, primary care physicians, community nurses, and community pharmacists).¹ In this decade, development and implementation of information-sharing tools have been mandated in medical service for cancer according to national policy in Japan.^{2,3} Unlike in many countries in the Europe, many patients do not have home physicians because Japan does not have a general practitioner (home physician) system; therefore, patients have direct access to all medical services under full coverage of the national insurance.^{2,4} Thus, a regional multidisciplinary palliative care team is organized by health care providers from different health care institutions when patients receive home-based palliative care.^{2,5}

The use of multidisciplinary teams is known to have a number of advantages, for example, medical staff on the team often complement each other, access to community medical resources increases, and the quality of life (QOL) of patients

is improved^{6,7}; thus, the use of multidisciplinary teams is recommended in various fields, including palliative care.⁷ Previous studies suggested that many Japanese patients would choose to receive home-based palliative care. The number of patients who chose home-based palliative care was limited, however, because there are not enough home palliative care resources available for patients in Japan or patients usually do not have exact information about whether home palliative care resources are available.^{8,9} In this last decade, the

¹ Department of Medical Oncology, Toyama University Hospital, Toyama, Japan

² Board of Palliative Care, Saiseikai Takaoka Hospital, Toyama, Japan

³ Home Palliative Care Committee, Takaoka Medical Service Region, Takaoka, Japan

⁴ Department of Palliative and Supportive Care, Seirei Mikatahara Hospital, Shizuoka, Japan

⁵ Kyowa Hakko Kirin Co, Ltd, Tokyo, Japan

⁶ Department of General and Digestive Surgery, Himi Municipal Hospital of Kanazawa Medical University, Japan

Corresponding Author:

Kouichi Tanabe, Department of Medical Oncology, Toyama University Hospital, 2630 Sugitani, Toyama City, Toyama Prefecture 930-0194, Japan.
Email: tanabeko-mi@umin.ac.jp

government strongly facilitates to increase the number of patients who receive home-based care, and information sharing among the staff in such teams would become increasingly important.¹

Patient-held records are one of the information-sharing instruments used in regional palliative care.^{2,10} Although previous studies have described some advantages of such records for health care providers,^{11,12} their use has been limited by the following 2 factors^{10,11}: (1) health care providers do not fully understand the roles and importance of patient-held records and (2) patients (and their relatives) have little awareness of their ability to manage their own medical records and become actively involved in their own care. Therefore, if information-sharing instruments are developed to be free from these limitations, while retaining the previously reported advantages associated with patient-held records, these instruments may be accepted by community health care providers as well as patients and their relatives, which should facilitate home-based palliative care.

Clinical pathways have previously been reported to be useful for improving the quality of palliative care provided by multidisciplinary care teams.¹³ Clinical pathways are utilized in overview (schedule) or checklist format,^{13,14} and integrated care pathways employing a checklist format,¹⁵ which were proposed by Ellershaw et al, are particularly appropriate for patients with terminal cancer.¹⁵

In the present study, we developed a Regional Clinical Referral Pathway for Home-Based Palliative Care (RRCP-HPC), a novel information-sharing instrument based on the framework of integrated care pathways, and evaluated its feasibility and practitioner-perceived usefulness.

Methods

Overview

The study took place between October 2011 and October 2013. The present mixed-method study was comprised of the following 2 types of collected data: (1) a quantitative study evaluating the frequency at which the target outcome was achieved, the frequency of variance from the pathway, and the mean number of records produced each day and (2) a qualitative study in which the usefulness of the RRCP-HPC and obstacles to its dissemination were evaluated by interviewing health care providers.

Development of the RRCP-HPC

When choosing the team used to develop the RRCP-HPC, we carefully selected health care professionals with more than 10 years of clinical experience from the Home Palliative Care Committee of the Takaoka Medical Service Region, which was established to resolve problems within the region and promote collaborations between health care providers, while trying to avoid choosing specific professionals. The program of RRCP is specifically for patients with cancer because

intense palliative care is covered only for patients with cancer by the national insurance in Japan. Therefore, to ensure that this novel tool was appropriate for use in patients with cancer receiving palliative care at home, the selected health care professionals, such as hospital physicians, primary care physicians, hospital nurses, home-visit nurses, pharmacists, medical social workers, managerial dietitians, physical therapists, and the palliative care team in the hospitals held several focus group discussions and referred to the findings of relevant studies.^{13,16-19} A pilot study involving a small number of patients was performed, and after several alterations had been made, the developers determined the criteria for employing the RRCP-HPC (ie, the patient has terminal cancer and wants home-based care, all of the patient's relatives have agreed that the patient should receive home-based palliative care, and the patient has no socioeconomic problems or, if they do, their problems are solvable) and defined the target outcome (dying at home), variance from the pathway (hospitalization), and other contents. The RRCP-HPC was placed in patients' homes, and the home visit medical staff and health care workers checked the written comments on the RRCP-HPC. The medical staff and health care workers who checked the RRCP-HPC gave comments and signed the free description sheets. We asked patients to use the telephone only in emergencies.

The RRCP-HPC is available at the following URLs:

1. <http://www.takaoka-saiseikai.jp/konwakai/img/path-jp-all.pdf> (in Japanese)
2. <http://www.takaoka-saiseikai.jp/konwakai/img/path-en.pdf> (in English)

The RRCP-HPC, which is presented in A4-size loose-leaf format, consists of the following 11 items: (1) information about the RRCP-HPC (its aim, significance, and how it should be used); (2) the patient's personal profile and contact numbers for use in case of an emergency; (3) the patient's medical information at discharge and personalized instructions for use by patients or their caregivers in case of an emergency; (4) the roles of primary care physicians and palliative care specialists; (5) the roles of other regional health care professionals; (6) information about home-based care and living; (7) a symptom assessment sheet based on the assessment schedules of the support team, a medical record sheet, and a free description sheet including a progress note for use by the multidisciplinary care team; (8) an overview of the pharmacotherapy prescribed at discharge; (9) evaluation criteria for use during assessments by the support team; (10) guidance on the regional medical services available; and (11) information about the economic support systems available for home-based care. Of the above-mentioned items, those items that need to be continually filled in are summarized in (7).

The RRCP-HPC is characterized by the following 3 factors: first, the tool provides instructions for predicting the symptoms that patients may exhibit and how rapid changes in each of these symptoms should be dealt with. The physicians who provide home visit medical care after discharge are able to change

these instructions at any time. Second, concerning the sheets mentioned in (7), 1 set should be used per day, and more sets can be issued if necessary because unpredictable events, such as sudden admission and death, can occur in cases involving patients with terminal cancer and it is, therefore, not possible to standardize the period of RRCP-HPC usage. Third, the tool should be regarded as being owned by patients and includes a free description sheet that can be used by patients and their relatives as a care diary. This sheet also serves as a progress note for health care providers, and, thus, is expected to encourage patients (and their relatives) to actively participate in their own care and communicate with health care providers.

Dissemination and Implementation of the RRCP-HPC

We held 6 lecture presentations and explanatory meetings for medical staff and health care workers about the usage of RRCP-HPC before its distribution. Thereafter, we distributed the RRCP-HPC to patients and their relatives during multidisciplinary pre-discharge conferences and gave all participants a full explanation of the tool's significance and its usage. The primary care physicians explained the significance of using the patients' own medical records to the patients in their care and noted that the RRCP-HPC belonged to the patients and that the taking of records was not for medical service workers but for the patient himself or herself. The patients and their relatives were encouraged to write any of their concerns (eg, accounts of the patient's treatment, any questions they had, and other relevant information) in the free comment spaces. The information written in RRCP-HPC was shared with the patient, the relatives, and all medical staff and health care workers when they visited. In Japan, it is not uncommon that patients do not have primary care physicians; hence, we asked patients to select their primary care physicians from general practitioners. The selected general practitioners who used the RRCP-HPC for the first time received on-the-job training for the first year of its distribution. Subsequently, we created DVDs containing information about the importance of the RRCP-HPC and instructions on how it should be used and distributed them to regional medical centers. The contents of the DVD are available for free at the following URL:

<http://www.takaoka-saiseikai.jp/konwakai/img/V9.wmv> (in Japanese)

Investigation of the Mean Number of RRCP-HPC Records Produced and Causes of Variance From the Pathway

Patients. Of the patients with terminal cancer referred to the palliative care team of Saiseikai Takaoka Hospital (Toyama Prefecture) between October 2011 and October 2013, all patients who participated in a multidisciplinary pre-discharge conference and consented to receiving home-based palliative care were enrolled. The observation period lasted for 3 months following enrollment. We excluded patients who were alive at the end of the observation period because the outcome could not be assessed in these cases, those who died before starting to

use the RRCP-HPC, and those from whom the RRCP-HPC could not be collected after their death for reasons such as the loss of the tool. The days of survival, palliative prognostic index, and performance status were recorded as patient characteristics from the day of the multidisciplinary pre-discharge conference which is performed a few days before discharge.

Determination of whether the target outcome was achieved. A previous Japanese study found that patients who died at home achieved a higher QOL than those who died in hospital, and caregivers and health care providers reported fewer difficulties when treating the former group² and hence, at-home death was selected as the target outcome.

Definition of variance from the pathway and classification of the reasons for such variance. In this study, patient hospitalization was defined as variance from the pathway regardless of the reason. On admission, the attending physician and palliative care specialists evaluated the patient and had consultations to determine the reason for their hospitalization, and this was subsequently entered into the patient's medical records. Variance from the pathway was not necessarily considered to be undesirable but rather was caused by the individuality of each case²⁰; therefore, no standardized criteria for assessing the incidence rate of variance exist. In the present study, we identified the reasons for variance (hospitalization) and categorized and summarized them according to the Classification of the Influence of Variance on Pathways issued by the Japanese Society for Clinical Pathways.²⁰ According to this classification method, variance events were classified into (1) no modification; that is, events after which it was possible for the patient to continue following the clinical pathway without modifications, for example, periods of brief hospitalization to provide caregivers with respite from their work, or scheduled hospitalization, such as the replacement of a gastric fistula catheter or a blood transfusion; (2) partial modification; that is, events after which it was possible for the patient to continue following a partially modified version of the clinical pathway, for example, emergency hospitalization in which specialized symptom control was required or pain, nausea, delirium, and dyspnea that were poorly controlled in home care; and (3) withdrawal; that is, events after which it was impossible to follow the clinical pathway, for example, when the patient died in hospital after readmission, regardless of the reason.

Calculation of the mean number of RRCP-HPC records produced each day. After a patient's death, we received their RRCP-HPC records with the approval of their families and analyzed the data. The mean number of RRCP-HPC records produced was calculated by dividing the number of times that the symptom assessment, medical record, and free description sheets were filled in by the number of days that the patient received at-home care (in other words, the number of days the RRCP-HPC had been used). The mean number of RRCP-HPC records produced each day was also calculated from the total of these

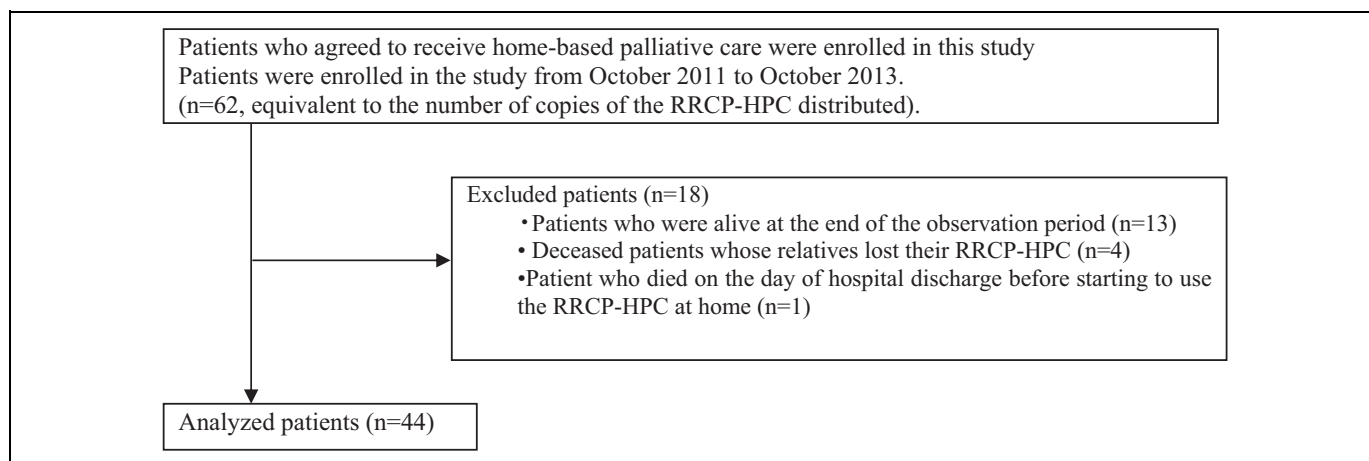


Figure 1. Flowchart of the participating patients.

3 sheets. In addition, to evaluate patients' (and their relatives') awareness of their ability to actively participate in their own care, the free description sheet was analyzed to obtain health care provider- and patient/family-specific data.

Interviews

Patients. Interviewees were chosen from among the primary care physicians, visiting nurses, community pharmacists, and care managers with experience of using the RRCPP-HPC, in descending order of their level of experience of the RRCPP-HPC and according to their professional field, and interviews were held until data saturation occurred.

Interview and questions. We conducted semistructured interviews with the interviewees for 45 to 60 minutes and recorded them using a voice recorder. The clinical research coordinator served as the interviewer.

The interview guide contained questions about the interviewees' overall impressions of the RRCPP-HPC including (1) the interviewees' impressions of the views of health care providers, patients, and patients' relatives regarding the usefulness and necessity of the RRCPP-HPC; (2) the interviewees' views about practical barriers to the use and dissemination of the RRCPP-HPC; and (3) the reasons why the interviewees gave the answers they did.

Analysis

Statistical analysis. We used the *t*-test, Mann-Whitney *U* test, chi-square test, or Fisher exact test for between-group comparisons based on the type of data being analyzed. The level of significance was set at .05. We also computed ϕ (Cramer *V*) and Cohen *d* values as measures of effect size. All statistical procedures were performed using SPSS version 22 (IBM Japan Ltd, Tokyo).

Content analysis. The audiotaped interviews were transcribed into text and anonymized. We then performed content analysis

of the data based on the methodology of Krippendorff.²¹ The patients' accounts on the usefulness of the RRCPP-HPC or barriers to its dissemination were extracted as a single record. The obtained accounts were classified and subjected to abstraction in an inductive manner according to their similarities, after which they were categorized by 2 independent researchers. During this process, the researchers held discussions until they reached an agreement.

Results

Target Outcome and Variance Frequencies

In this study, we distributed the RRCPP-HPC to 62 patients and analyzed 44 of them (Figure 1). Of the 44 patients who returned for follow-up visits after being discharged from the hospital, 1 patient was transferred to home palliative care after we held a conference that was equivalent to a predischarge conference on the patient's preferred day. Patient characteristics are shown in Table 1. During the study period, 19 clinics (19 primary care physicians), 9 home visit nursing stations, 15 community pharmacies, and 19 at-home, long-term care support business offices were involved in caring for the patients and used the RRCPP-HPC.

The target outcome was achieved in 61.4% of patients (95% confidence interval [CI]: 45.5%-75.6%) and variance occurred in 54.5% of patients (95% CI: 38.8%-69.6%). Regarding the details of variance events, variance was categorized as "no modification" in 1 patient who underwent respite-induced hospitalization; "partial modification" in 6 patients who had pain, vomiting, cholecystitis, obstructive jaundice, fractures, fever, or ascites puncture; and "withdrawal" in 17 patients who died in hospital after readmission. The main reasons for admission among the latter patients were a consciousness disorder or delirium (*n* = 6), abdominal pain, or perforation of the small intestine (*n* = 5), a lack of caregiving skills on the part of their relatives or respite-induced hospitalization (*n* = 3), dyspnea (*n* = 2), and cardiac failure (*n* = 1). All of

Table 1. Patient's Background Data Before Discharge.

| Characteristics | Value (N = 44) |
|------------------------------------------------------------|-----------------|
| Age, year (mean \pm SD) | 74.3 \pm 12.0 |
| Gender, n (Male/female) | 20/24 |
| PPI (score, mean \pm SD) | 3.8 \pm 2.5 |
| Days of home care, day (mean \pm SD) | 57.8 \pm 55.2 |
| Survival, (day, mean \pm SD) | 72.6 \pm 68.1 |
| Proportion of stay at home, % (mean \pm SD) ^a | 79.6 \pm 17.5 |
| ECOG PS, n (0/1/2/3/4) | 0/10/11/22/1 |
| Primary site | |
| Stomach/esophagus, n (%) | 15 (34.1) |
| Liver/biliary tract/pancreas, n (%) | 12 (27.3) |
| Large intestine, n (%) | 9 (20.5) |
| Lung, n (%) | 3 (6.8) |
| Others, n (%) | 5 (11.4) |

Abbreviations: PPI, palliative prognostic index; ECOG, Eastern Cooperative Oncology Group; PS, Performance Status; SD, standard deviation.

^a The rate of home care was calculated dividing the days of home care by survival after multidisciplinary pre-discharge conference.

these patients, except for those admitted due to a lack of caregiving skills on the part of their relatives or to provide their caregivers with some respite, were emergently transferred to hospital at the request of their primary care physicians.

Frequency of RRCP-HPC Record Use

The mean number of the symptom assessment, medical record, and free description sheets that were produced each day (mean \pm standard deviation) was 2.59 \pm 1.53. By sheet, the mean number of the symptom assessment and medical record sheets produced each day was 0.54 \pm 0.34 and 0.66 \pm 0.37, respectively. The free description sheet was completed 0.93 \pm 0.56 times per day by health care providers and by 0.40 \pm 0.72 times per day by the patients or their relatives.

Usefulness of the RRCP-HPC and Obstacles to its Dissemination According to Health Care Providers

We finished performing interviews when data saturation occurred at the eighth interview. The 8 chosen participants included 2 primary care physicians, 2 visiting nurses, 2 community pharmacists, and 2 care managers. Using content analysis, we obtained 49 meaningful records and established 9 categories related to the usefulness of the RRCP-HPC and 4 categories associated with obstacles to its dissemination (Table 2). The names of each category and examples of the interviewees' accounts are shown subsequently.

Usefulness of the RRCP-HPC. To clarify the interviewees' overall impressions about the RRCP-HPC, we asked them at the beginning of each interview whether they considered home-based palliative care to be useful, and all 8 interviewees responded that it was. By then asking them in detail about their perceptions regarding how each stakeholder viewed the usefulness of the tool, we extracted the following 9 categories (Table 2):

Table 2. Health Care Provider-Perceived Usefulness of the RRCP-HPC and Obstacles to its Dissemination.

| Themes/categories | Number of meaningful records | |
|---------------------------------------------------------------------------------|------------------------------|---------------------------------|
| | For health care providers | For patients and their families |
| Usefulness | 29 | 8 |
| A tool for reviewing patients' conditions | 8 | 3 |
| A communication tool | 5 | 2 |
| A standardized symptom-assessment tool | 4 | 0 |
| An information-sharing instrument | 4 | 0 |
| Effective at strengthening psychological relationships | 3 | 2 |
| Easy to use | 3 | 0 |
| An educational tool | 1 | 0 |
| Effective at motivating health care providers | 1 | 0 |
| Helps to maintain the connections between deceased patients and their relatives | 0 | 1 |
| Obstacles | 11 | 1 |
| Specific types of professionals more likely to act as recorders | 3 | 1 |
| Issues regarding the format of the RRCP-HPC | 3 | 0 |
| Increase in the amount of paperwork | 3 | 0 |
| More patient information needed | 2 | 0 |

Abbreviation: RRCP-HPC, Regional Clinical Referral Pathway for Home-Based Palliative Care.

(1) "Useful as a tool for reviewing patients' disease conditions"; (2) "Useful as a communication tool"; (3) "Useful as a standardized index for symptom evaluation"; (4) "Useful as a tool for sharing information"; (5) "Effective at strengthening psychological relationships among health care providers, patients, and patients' relatives"; (6) "Easy to use"; (7) "Useful as a tool for educating health care workers"; (8) "Effective at motivating health care providers"; and (9) "Helpful for maintaining the connection between patients and their relatives even after the patient's death."

Concerning (1) "Useful as a tool for reviewing patients' disease conditions," the RRCP-HPC was perceived to help health care providers and patients/their relatives to understand the patient's disease condition and treatment course. The following are examples of the statements the interviewees made about this topic:

I think that the RRCP-HPC is very useful because the patients' information is summarized in their RRCP-HPC and can be reviewed at any time. (Interviewee No.3: a care manager)

The RRCP-HPC is very helpful. Patients' information, including their current conditions and medical histories, is clearly shown in their clinical pathway documents; therefore, healthcare providers,

including those who first participate in a patient's care when they are halfway through the pathway, have no difficulty understanding their progress. (Interviewee No.5: a pharmacist working at a health insurance pharmacy)

The RRCP-HPC is useful for patients and their families in that they can easily check patients' symptom changes and treatment courses. (Interviewee No.2: primary care physician)

Concerning (2) "Useful as a communication tool," the interviewees mentioned that as many health care providers, including physicians, check patients' RRCP-HPC documents before visiting them, the RRCP-HPC helps patients to ask questions to their health care workers. In addition, they also highlighted the importance of the free comment space. The following are examples of the statements the interviewees made about this topic:

The needs of patients receiving home-based care change constantly, and healthcare providers, such as physicians, nurses, pharmacists, and others, welcome the opportunity to give their comments. Therefore, spaces that are large enough to write comments in are very useful when palliative care is provided by a multidisciplinary team. (Interviewee No.2: primary care physician)

Each caring professional records any progress in the patient's RRCP-HPC from his/her own viewpoint, and these records can be reviewed by other healthcare providers. Thus, this tool facilitates information-sharing among caring professionals without having face-to-face discussions. If any professional's written comment seems debatable, we can mark it and receive a response from him/her later. Organizing face-to-face meetings is demanding as it often requires adjustments to our schedules. Thus, the RRCP-HPC is far superior to other tools in that it allows discussions to take place in written form. Thus, the tool is essential for home-based palliative care. (Interviewee No.1: primary care physician)

The RRCP-HPC is of value because the patients' attending physicians also review my comments. (Interviewee No.6: a home-visit nurse)

When patients were unsure about some information in their RRCP-HPC, they could receive explanations in a manner appropriate to their understanding from caring professionals on another day. In that sense, the tool is useful. (Interviewee No.3: a care manager)

Concerning (4) "Useful as a tool for sharing information," the interviewees mentioned that using the RRCP-HPC they were able to share information on patients' current symptoms and the course of symptom control. In addition, they indicated that the tool is also useful for information delivery. The following are examples of the statements interviewees made about this topic:

When providing home-based palliative care, there are advantages in using the RRCP-HPC, such as it specifies patients' current disease conditions and emergency contact numbers. (Interviewee No.7: a care manager)

Nurses and physicians commonly work in pairs and understand each other well. However, pharmacists working at health insurance pharmacies do not have much contact with nurses and often find it difficult to work in a team unless they obtain the necessary information from patients' RRCP-HPC. (Interviewee No.8: a pharmacist working at a health insurance pharmacy)

The RRCP-HPC is very useful in that it allows pharmacists to inform other healthcare providers about the drugs that have been prescribed. (Interviewee No.5: a pharmacist working at a health insurance pharmacy)

Concerning (5) "Effective at strengthening psychological relationships among health care providers, patients, and patients' relatives," the interviewees highlighted the importance of the RRCP-HPC and indicated that it helped to strengthen the psychological relationships among health care providers, patients, and patients' relatives. The following are examples of the statements the interviewees made about this topic:

If patients have their own RRCP-HPC, it helps them and their relatives to recognize that their physicians and nurses provide care in a cooperative manner and feel like they are actively involved in their own care. In addition, the tool functions to bring healthcare providers and patients/their relatives together." (Interviewee No.6: a home-visit nurse)

Each healthcare worker in the team writes his/her comments in the free spaces when visiting patients, and because of this, I realize that I am not the only one caring for my patients and that us caregivers are connected to each other through our patients. This is very encouraging. (Interviewee No.4: a home-visit nurse)

Exchanging opinions based on patients' RRCP-HPC in order to improve their care may lead to increased cooperation among healthcare providers, patients, and patients' relatives. (Interviewee No.6: a home-visit nurse)

An interviewee who had previously visited the family of a patient who died also talked about (9) "Helpful for maintaining the connection between patients and their relatives even after the patient's death" as follows:

The RRCP-HPC helps patients with a limited life expectancy to record their lives, and such records are very valuable as the relatives of deceased patients can reflect on them. (Interviewee No.4: a home-visit nurse)

Obstacles to the dissemination of the RRCP-HPC. We asked interviewees to talk about factors that they considered to be barriers to the dissemination of the RRCP-HPC, and content analysis resulted in the extraction of the following 4 categories (Table 2): (1) "Certain types of professionals are more likely to act as recorders", (2) "Issues regarding the format of the RRCP-HPC", (3) "An increase in the amount of paperwork required", and (4) "A desire for the RRCP-HPC to contain more patient information."

Regarding (1), the interviewees reported that it was important to constantly encourage caring professionals to record

information in the RRCP-HPC. An example of the statements made by the interviewees regarding this topic is given below:

The information recorded in the patients' RRCP-HPC is easily accessible, and, thus, we need to encourage all individuals involved in patient care to fill in their clinical pathway documents whenever possible. (Interviewee No.8: a pharmacist working at a health insurance pharmacy)

Concerning (3), the interviewees mentioned that the dissemination of the RRCP-HPC is limited by the presence of other tools for recording care and practitioners in some professions being legally required to produce records using other tools. The following are examples of the statements the interviewees made about this topic:

In addition to the RRCP-HPC, we have a tool called the Care Reporting Notebook in Takaoka City, and patients who have been certified as requiring care use this notebook. Thus, there is some overlap between the contents of the Care Reporting Notebook and the RRCP-HPC. (Interviewee No. 7: a care manager)

Particularly at home-visit nursing stations, staffs are required to deal with various documents; therefore, it would be preferable if nursing and RRCP-HPC records could be combined. (Interviewee No. 4: a home-visit nurse)

Regarding (4), the interviewees reported that it would be beneficial if certain additional types of information were recordable in the RRCP-HPC in order to allow it to be used as a standardized tool. The following is an example of the statements the interviewees made about this topic:

At present, home-based care involves reporting and recording notebooks. If we use the RRCP-HPC as a standardized tool, some of the information that can be written in these notebooks may not be recordable in the RRCP-HPC. From a nursing viewpoint, it is desirable to have spaces in which we can record the details of patients' lives, such as information about their toileting, physical hygiene, and eating habits. It should also be easy to review the recorded information. Although the RRCP-HPC is mainly used to record information about palliative care, such as pain relief, I would like to stress that such care is markedly affected by the patients' daily lives. (Interviewee No. 6: a home-visit nurse)

Discussion

Although previous studies reported on information-sharing instruments in the field of home-based palliative care,^{2,10-12} to the best of our knowledge, the present study is the first to examine the feasibility and practitioner-perceived usefulness of a regional clinical referral pathway involving a predefined target outcome and variance categorization system.

We were able to employ the RRCP-HPC throughout the study period (2 years) in a real-world setting, and it was demonstrated as feasible, based on the frequency at which the target outcome was achieved, the incidence rate of variance

events, and the mean number of RRCP-HPC records produced each day. Among the group that had withdrawn from the pathway, the most common reasons for hospital admission, except respite-induced hospitalization, all involved symptoms that were difficult to relieve with measures other than sedation due to their rapid onset/exacerbation (eg, dyspnea, irreversible delirium, and perforation of the small intestine). On the other hand, no or partial modification occurred less frequently than withdrawal, and it was possible to deal with the symptoms displayed by these patients at home. This result suggests that these 2 types of variances did not strongly hinder implementation of the RRCP-HPC. The patients or their relatives also filled in the free description sheet approximately 0.4 times a day, which was approximately 50% lower than the frequency exhibited by health care providers, indicating that patients or their relatives used the RRCP-HPC once for every 2 health care provider visits. Although it is difficult to discuss whether this frequency was sufficient because of the absence of comparable studies, our results suggest that patients (and their relatives) became actively involved in their own home-based palliative care.

The interviews clarified that the RRCP-HPC was perceived to be useful for symptom evaluation; educating health care workers; strengthening psychological relationships among health care workers, patients, and patients' relatives; motivating health care workers; and maintaining connections between deceased patients and their relatives. Although studies on the utility of patient-held records as an information-sharing instrument have revealed certain merits, for example, they promote information sharing, nurture communication between health care providers and patients/their relatives, and lead to a better understanding of patients' symptoms and treatment courses.^{2,10-12} The results of our study suggest that the RRCP-HPC has further advantages in addition to those mentioned earlier. On the other hand, health care providers' poor understanding of patient-held records and the low level of awareness among patients (and their relatives) of their ability to actively participate in their own care are issues that need to be addressed.^{10,11} However, based on the mean number of RRCP-HPC records produced by the patients/their relatives each day and the health care providers' thoughts regarding the usefulness of the RRCP-HPC and its benefits for patients and their relatives, the RRCP-HPC is less likely to be affected by the above-mentioned issues. This may be due to the RRCP-HPC administration strategies we employed; that is, we explained the importance of the tool and distributed a DVD version of its manuals. Other issues included specific types of professionals being more likely to act as recorders, an increase in the amount of paperwork that needed to be completed, overlapping between the contents of records produced using different tools, and requests to make it possible to record other pieces of relevant information in the RRCP-HPC. Concerning specific types of professionals who were more likely to act as recorders, the importance of the RRCP-HPC may not be sufficiently understood by having a multidisciplinary predischarge conference or distributing a DVD version of its manuals. It may be necessary to conduct administrative interventions, such as caring team members

encouraging others in the same team to fill in patients' RRCP-HPC whenever possible. Furthermore, because recording other relevant information in the RRCP-HPC and decreasing the amount of paperwork that needs to be completed are in a trade-off relationship, it may be challenging to achieve these 2 goals simultaneously. Previous studies on the utility of patient-held records reported that it was inappropriate for such records to include sensitive information (eg, patients' privacy) or information that patients did not want to know¹⁰; therefore, it may be possible to resolve these issues using different types of information-sharing instruments alone or in combination according to the type of information, required timelines of information sharing, and caring team members' information technology literacy.

The interviews indicated that one of the reasons why patients considered the RRCP-HPC to be useful was because it helped to maintain connections between deceased patients and their relatives. As it would be difficult to achieve this by using computerized tools, the patient-held nature of the RRCP-HPC is clearly beneficial for patients and their families.

There were some notable limitations to the present study. First, its findings may not represent the situation in the whole of the target district due to the small number of patients involved and only one acute care hospital participating; that is, supported its home-based palliative care team. To evaluate the reproducibility and generalizability of our results, it will be necessary to conduct a multicenter study involving several such hospitals in other districts. Second, the usefulness of the RRCP-HPC was evaluated qualitatively but not quantitatively in this study; that is, we did not assess any quantitative outcomes or make before and after comparisons; hence, we need to further examine the utility of the RRCP-HPC. Third, since the RRCP-HPC was not evaluated by patients, our study may not have accurately recorded the views of patients (including deceased individuals) or their relatives regarding the usefulness of the RRCP-HPC or obstacles to its dissemination. Fourth, although data saturation occurred, we might not have obtained minor opinions because the number of interviewees was small. Fifth, as this study was performed in a clinical setting, various interventions other than the RRCP-HPC were implemented during the study period according to the patients' conditions. Therefore, our results may have been confounded by these interventions. This study was preliminary and involved the above-mentioned limitations. However, we could employ the RRCP-HPC, which is free from some of the issues that affect other information-sharing tools but retains the advantages of patient-held records, in a real-world setting for approximately 2 years and clarified its feasibility and usefulness. We were also able to obtain basic data that can be used in future studies to examine the optimal combinations of information-sharing tools, further improve the RRCP-HPC, or evaluate its reproducibility and generalizability.

In conclusion, we developed the RRCP-HPC, a novel patient-held, information-sharing instrument, and examined its feasibility and usefulness in the present study. This clinical pathway is feasible and appears to be useful in summarizing patients'

conditions, communication/relationships, symptom evaluations, information-sharing, and education. Further studies are warranted to examine the impact of this pathway on patient outcomes.

Authors' Note

Kouichi Tanabe and Koichiro Sawada contributed equally to this study.

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